

# ANALYSIS OF OUTCOME-BASED QUALITY ASSURANCE SYSTEMS

## TASK A REPORT



Submitted to: Health Care Financing Administration

Submitted by: Human Services Research Institute

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Jaskulski and Associates

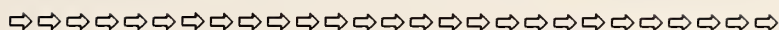


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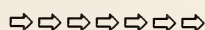
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## TASK A REPORT

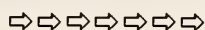
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**Report #1**  
**State Quality Assurance Systems**

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**ANALYSIS OF OUTCOME-BASED QUALITY  
ASSURANCE SYSTEMS**

**Report #2**  
**Analysis of the Application of the Active Treatment Definition**  
**(Objective 5, Task A)**

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**REVIEW OF THE CURRENT DEFINITION OF ACTIVE  
TREATMENT AND RELATED ICF/MR QUALITY  
ASSURANCE ACTIVITIES**



**Report #1**  
**State Quality Assurance Systems**

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**ANALYSIS OF OUTCOME-BASED QUALITY  
ASSURANCE SYSTEMS**



**REPORT #1**  
**STATE QUALITY ASSURANCE SYSTEMS**  
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**Report #1**  
**State Quality Assurance Systems**

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**ANALYSIS OF OUTCOME-BASED QUALITY ASSURANCE  
SYSTEMS**

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**I. INTRODUCTION AND RATIONALE**

The following report, funded by the Health Care Financing Administration, provides an overview of significant changes taking place in the field of quality assurance in mental retardation and developmental disabilities, analyzes the qualitative and quantitative properties of these changes, and contrasts these emerging trends with current federal regulatory practices.

The increasing emphasis on outcomes as a mode for monitoring the quality of services to people with mental retardation and other developmental disabilities is more than merely a change in measurement approaches. It represents a change in the expectations regarding what is a "quality" service and, as such, is part of a much larger shift in the field; specifically from program-oriented, formulaic models of care to individually tailored supports based on individual choices and preferences. As a result, the infusion of outcome-oriented quality assurance techniques is both the result of the change in expectations as well as a method for expediting the shift at the provider level. There are a variety of reasons why this shift has taken place:

- The expectations of people with disabilities and their families regarding the quality of services has changed as fewer people have been placed in institutions, as more people are included in their local service systems, and as policies regarding empowerment of people with disabilities and their families have become more widespread (e.g., expansion of family support, the adoption of person-centered planning, etc.)
- Quality assurance mechanisms have evolved as the system has evolved and become more competent: input approaches were needed when the major goal of public policy was provide for people's basic need; process measures were needed when the emerging technologies and interventions needed to be codified and expanded; and outcome measures are needed now to ensure that those technologies are in fact resulting in an improved quality of life for those being served and supported.

- In order to provide individually tailored supports, it is necessary to allow a certain amount of flexibility for innovation and creativity. Certain process requirements are seen by some providers and policy makers as constraining innovation whereas outcome measurements allow for more flexibility.
- Quality assurance systems that rely on punishment and sanctions were probably suited to a period when the state of the art was not broadly understood and when the basic concerns had to do with people's physical well-being. They are also more consistent with periods of time when there is a shared orthodoxy, a standardization of service models, and a more hierarchical administrative structure for providing services. The emergence of the supports model moves away from standardized methods of providing services and requires a less standardized and therefore less sanction oriented method for assessing quality.
- Finally, and linked to the point above, the growth of continuous quality improvement and total quality management initiatives has strongly influenced the tenor of quality assurance and has shifted the focus of QA from process oriented measures to customer satisfaction, and from deficit spotting to quality enhancement.

Thus the larger context for this project is not simply an analysis of new techniques but also the context of the larger reform within which they are taking places. Some of the forces at work in the states and nationally include the following:

- **Reduction in number of ICF/MR beds** A general observation of the states visited is the rapidity with which some states are reducing the number of ICF/MR beds in the public as well as the private sector. In Massachusetts, all community ICF/MR beds have been converted to waiver status. In Colorado, there are only 300 beds left in the whole state. This reduction raises the question of the continuing relevance of a separate ICF/MR regulatory framework and the possibility of a combined waiver/ICF/MR quality assurance approach. As more and more Medicaid-funded residences are under the waiver, there were also concerns raised in some states about the adequacy of waiver quality assurance approaches. In New York, for example, the state was in the process of reorganizing and recentralizing quality assurance monitoring for waiver facilities given what were said to be some examples of inadequate oversight.
- **Impact of Resource Cut-Backs** In many of the states visited, cutbacks in central office staff had already taken place and/or were planned for the future. Therefore, it is clear that any labor intensive, highly systematic approach to the collection of outcome and quality assurance information will be difficult if not



impossible to implement in those states (e.g., CO) where the central office staff is diminishing. Though not all of the states visited had undergone such cutbacks, it is likely -- given the changes taking place in federal funding -- that there will be cutbacks in other states such as New York and Massachusetts. This suggests that approaches such as the QUEST in Massachusetts will be hard to transfer to small central office states.

It is also interesting to note that many of those states that had more labor-intensive approaches to quality assurance (e.g., Oklahoma, Pennsylvania, Massachusetts, and Oregon) were under a variety of federal court mandates that required the installation of systematic quality assurance measures.

- **Reduction in Case Management Resources** Again, the cut-back in resources at the state level is having an impact on the presence of case managers and the numbers of people on their caseloads. Given that case managers are sometimes viewed as the front-line of a quality assurance system and, in some instances, the collectors of QA information, this diminution of capacity should be noted. The roles of case managers in many states are also changing as states like New Hampshire are moving to a service broker or support person approach in which the staff person acts a collaborator with the person with a disability and the family to secure specialized as well as generic supports. Thus while conventional case management functions may be decreasing, the new roles for service brokers may mean that will be even better informants regarding outcomes for particular individuals.
- **Impact of Decentralization** Many states are moving to significantly decentralize responsibility and authority for the provision of services to people with mental retardation and other developmental disabilities. In Colorado, for instance there is a proposal to decentralize the system to the community-centered board which would function as a mini "managed care" entity. While the state will likely maintain some quality assurance responsibility, other QA functions will undoubtedly be moved to the community level. This devolution of responsibility raises questions regarding the roles that will be played by the state versus local entities and the nature of the level at which accountability for service quality and outcomes will be lodged.
- **Integration of Services** While it is only an emerging trend, the move to combine services across disabilities -- especially at the state level, is beginning to take hold in some states. In Massachusetts, there is a proposal to merge mental retardation services with services to people who are deaf, and to people who are blind. In New Hampshire, there is a proposal to combine services to people with developmental disabilities with services to the elderly. In Georgia, the state has consolidated mental health, mental retardation, and substance

abuse services under a regional administration and is currently developing unified performance indicators across the three disabilities. This move to integrate services, based in part on cost concerns, may result in more generic quality assurance measures over time.

- **Relevance of Managed Care** While there are currently no managed care waivers approved for managed care in long-term care for people with mental retardation and other developmental disabilities, there are plans in virtually every state to develop waiver proposals. The interjection of managed care has profound implications for the role of the federal and state government in quality assurance and such considerations should be part of any reconstituted federal quality assurance guidelines. Specifically, some data collection and oversight functions may be delegated to private managed care companies. In Georgia, for instance, the state is currently contemplating requiring managed care companies to develop their own accreditation mechanisms. The advent of managed care may also further accelerate the decline in the utilization of more expensive ICF/MR beds.

The following report is organized into nine parts: Part II includes a summary of the methodology that governed the various project activities; Part III provides a summary of the findings from the 50 state survey of quality assurance methods; Part IV provides a summary of the findings from the literature review of outcome and other research; Part V provides a summary of the findings and themes from the 8 state site visits; Part VI provides a summary of the results of the reliability and validity analyses of outcome-based state and accreditation instruments as well as the findings from the health and safety surveys, Part VII presents findings related to the examination of performance indicator data bases; Part VIII provides an analysis of the application of the current ICF/MR active treatment regulations and their relationship to outcome-focused QA approaches; and Part XIX includes a summary of conclusions and recommendations.



## II. METHODOLOGY

In order to explore the ramifications of the emerging outcome orientation in quality assurance for the exercise of federal regulatory authority under the regulations governing Intermediate Care Facilities for People with Mental Retardation (ICFs/MR), the Health Care Financing Administration contracted with Human Services Research Institute (HSRI) to conduct an analysis of state outcome assessment practices, performance indicator systems, and the extent to which current the active treatment framework in federal rules is consistent with burgeoning outcome oriented certification approaches. The project was carried out in collaboration with Temple University Institute on Disabilities and Jaskulski and Associates. To complete the project, three major tasks were undertaken:

- Task A: Evaluation of the ICF/MR Program Quality Assurance System;
- Task B: Identification and Evaluation of Quality Indicators (submitted as a separate report);
- Task C: Establish a Baseline of Current Psychoactive Drug Utilization in ICFs/MR (submitted as a separate report).

To ensure advice from a broad array of constituencies, a Technical Working Group was appointed in collaboration with the HCFA project director. The Group included representatives of major advocacy organizations, accreditation bodies, provider agencies, researchers, and family members and people with mental retardation.

The research objectives in the approved research plan addressed in Task A are as follows:

- To summarize the "state of the States" in outcome-based quality assurance for ICF/MR facilities and for facilities/residences serving comparable individuals;
- To conduct an in-depth review and analysis of such systems in 8 States;
- To assess the reliability and validity of the selected quality assurance systems;
- To identify and review empirical studies of outcome-focused quality assurance systems;

- To analyze application of the current ICF/MR active treatment definition and its consistency with current concepts of support;
- To identify implications for changes in the current ICF/MR quality assurance system.

The methods and activities carried out to address each objective are described below.

**Objective 1: To summarize the "state of the States" in outcome-based quality assurance for ICF/MR facilities and for facilities/residences serving comparable individuals.**

The first step in studying the "state of the states" was to collect and compile information on current state quality assurance approaches. A wide range of published and unpublished sources of information, covering both state systems and other quality assurance systems of interest was canvassed. Throughout all of the activities, outcome-focused systems referred to systems that focus on the primary outcomes of interest as outlined in HCFA's Request for Proposal: Individualization, Integration/Inclusion, Relationships/Social Connections, Health and Safety, Personal Growth, Self-determination, Dignity, and Consumer Satisfaction

A telephone inquiry was conducted with individuals in each of the 50 states and the District of Columbia. Specifically, the survey was targeted to officials at the state mental retardation/developmental disabilities department most knowledgeable about the state's quality assurance system. In some states where separate QA systems were in place for Medicaid waiver programs, staff also contacted individuals in the state Medicaid agency. A full listing of all key informants is included in Appendix A of this report. Questions from an inquiry guide were asked of all contacts concerning the extent to which the primary outcomes were being used, what data are collected on primary outcomes, methods and measures used (including information about reliability and validity of the measures) and effectiveness of outcome-focused systems. The results of these inquiries are summarized below and described in more detail in "Compendium of State Outcome-Focused Quality Assurance Systems," the interim report for Task A submitted to HCFA in July, 1995.

**Objective 2: To conduct an in-depth review and analysis of such systems in 6-8 States.**

In order to select the 8 systems for in-depth review, the following criteria were developed in conjunction with HCFA:



- The presence of a quality assurance system that employs measurements of client circumstances that coincide with the selected outcomes;
- The availability of quality assurance information regarding health and safety as well as client outcomes;
- The presence of a data collection instrument that has been validated and tested for reliability;
- The presence of other empirical analyses of the quality assurance data base that related to its effectiveness and/or reliability;
- Application of a quality assurance measure on clients in a range of residential contexts including ICFs/MR -- private and public;
- The presence of an innovative quality assurance system that has been in place for at least a year and preferably longer;
- Willingness of state and/or agency administrators to assist in validation and reliability process.
- The presence of innovative waiver and or CSLA QA mechanisms.

Though no state met all of the criteria, eight states had a sufficient complement of the components noted above and were proposed as potential site visit states. Recommendations were made to members of the Technical Working Group, who ranked their selections in order of priority. Initially, six states were chosen; two additional states were added after HCFA provided additional resources. The eight states visited were Massachusetts, Missouri, New York, Oklahoma, Oregon, Utah, Colorado and Wyoming. The State of Wyoming was subsequently eliminated from the analysis because of the formative nature of the quality assurance system and the lack of any systematic data. Prior to the site visits, an interview guide was developed which covered the following areas:

- The ways in which the quality assurance process was developed and the extent to which it represents a consensus across the various constituencies in the state (e.g., providers, clients, families, advocates, etc.);
- Development of outcome-focused quality assurance in the state, including the impetus, level of consensus and service system trends
- The outcomes being measured, including how selected, applicability to individuals with severe disabilities;

- The role of the quality outcome system in the states residential services quality assurance, including how related to compliance standards and health and safety measures; and the extent to which current QA procedures protect the health and safety of persons using residential services and supports;
- Perceived effectiveness of the state's quality assurance approaches and relevance to the valued outcomes;
- Use of quality assurance information to enhance and improve services;
- Comparisons of experiences with the ICF/MR regulations and state QA approaches.

One to two staff from HSRI spent two to three days in each state conducting interviews with key stakeholders including: state officials, state quality assurance personnel, providers, representatives of advocacy organizations, directors and staff of ICFs/MR, ICF/MR surveyors, and individuals who live in residential programs and their families. Providers, advocates and consumers were usually interviewed in groups and interviews were conducted both in the state capitol and in at least one other area of the state. Site visit reports were drafted and sent to the state for comments.

In addition to the eight states, project staff also reviewed implementation of the new (1993) Outcome-based Performance Measures developed by the Accreditation Council and the new (1995) standards for community support accreditation from CARF.

In addition to the qualitative assessments in each state, HCFA has required that "the contractor shall identify the degree to which the outcome of protection of beneficiary health and safety, is present in each system." In order to respond to that issue, Temple developed a Health and Safety Issues instrument. The instrument includes information about medications, unusual incidents, behavior programs and safety within the residential setting. Data was collected in each of the eight states for a sample of at least 30 individuals. Interviews were typically conducted with direct care staff who knew the individuals well; however, whenever possible, individuals were invited and encouraged to participate in the interviews. A copy of the Health and Safety Instrument can be found in Appendix B.

In addition to collecting original health and safety data, Temple staff reviews collected other data with which the health and safety data can be compared including: outcome data, licensing data, OSCAR data (for ICFs/MR) and any other quality assurance data collected by the state on an ongoing basis. The purpose for gathering these data is to



determine the extent to which states' quality assurance systems capture information regarding beneficiary health and safety.

**Objective 3: To assess the reliability and validity of the selected quality assurance systems.**

In addition to the qualitative assessments being performed as part of the Task A analysis, it was determined by both the contractor and HCFA that any outcome-based system that is recommended contain strong statistical properties such as reliability and validity. In particular the study team agreed upon the following statistical measures to assess the instruments used to measure quality outcomes for individuals, programs and agencies.

***Reliability***

The study team has attempted to ascertain the extent to which the instruments used possess inter-rater reliability; the extent to which two raters score information about an individual in the same way. The first step in this process was to determine whether states had completed their own reliability studies. If so, those studies were obtained and reviewed. In those cases where the studies established statistically significant reliability coefficients, the reports were summarized and are part of the state summaries of quantitative findings in Appendix C. In those states where reliability data have not been collected, or have not been collected in several years (e.g. Colorado) additional data collection was necessary. To complete inter-rater reliability studies, typically two data collectors collect information about the same individual from the same respondent with a relatively short period of time elapsing between data collections. In order to complete this activity, on-site review in the individual state was not always necessary. In some cases, the instruments used in each of the states could be brought to Pennsylvania. When that was determined to be appropriate, the instruments were administered in the residential service system in Pennsylvania by two separate raters.

From a research perspective, reliability studies are also helpful in that they often point to the need for additional or more consistent training of interviewers, to insure that data are collected consistently, regardless of who collects the data. Many of the states and entities (AC and CARF) have developed instrumentation that is premised upon extensive training and re-training of data collectors.

As we have determined through the site visits to the eight states and the observation of both AC and CARF surveys, some of the instruments that have been developed require extensive training and require several days to complete the ratings for one individual.

Particularly in the case where extensive training is required, (e.g. AC, CARF) importing instruments to Pennsylvania was determined to be inappropriate (from a research perspective), by both members of the study team and by the individuals responsible for implementation of the quality assurance systems in each of the states. Additionally, the burden of asking the states/entities to perform the required re-surveys would have been excessive. Fortunately, in many cases the states/entities have already embarked upon reliability studies of their own. The data from those studies is summarized and included in the state summary reports.

As part of the outcomes survey process, the Accreditation Council pays significant attention to the issue of inter-rater reliability. As part of each outcome survey, data are collected by at least two reviewers during an interview. One of the two individuals leads the interview; however, both individuals complete ratings for the individual interviewed. These data are currently being collected and analyzed by Johns Hopkins University. Once a preliminary report is issued, we will review it and share it with HCFA.

CARF has not yet been involved in the process of establishing reliability of the outcome standards. Because of the intensity of the accreditation process and the training assumptions for conducting reviews, the Study Team determined it was inappropriate to conduct a reliability study of CARF. Similarly, because of the intensity and length of the process, providers were unwilling to submit to additional surveys for purposes of this study.

For the states where Temple has conducted the reliability study (New York and Colorado), data were collected by a reviewer trained by the Study Team. Approximately two to four weeks after the initial data collection, a second reviewer was sent to complete data collection instruments with the same respondent used for the first data collection. Data were collected for this part of the project in a large, public ICF/MR; a large, private ICF/MR; and several small, private ICFs/MR.

### *Concurrent Validity*

In this portion of the study, the study team is measuring the extent to which the instruments used measure the same underlying dimensions as other instruments that have established properties of reliability and validity. The instrument chosen for comparative purposes was the Behavior Development Survey, an instrument used and modified by Temple University for more than 15 years. A copy is included in Appendix B of this report. The instrument has been proven reliable (Devlin, 1981) and includes many of the valued outcomes identified by the HCFA work group including:



- Individualization;
- Integration/Inclusion;
- Relationships/Social Connections;
- Health and Safety;
- Personal Growth;
- Self-determination;
- Dignity; and
- Consumer Satisfaction.

Again, the first step in this process was to determine whether the states had undertaken their own studies of concurrent validity. For those states that have completed studies, the studies have been requested, received and evaluated by the study team. If they have been deemed acceptable (demonstrating statistically significant correlations) the studies have been summarized and included as part of the state summaries in Appendix C. For those states where concurrent validity has not been tested, data collection has occurred. In those situations where Pennsylvania staff could be easily trained to apply an instrument and where the instrument could be applied in a reasonable amount of time, the instrument was imported to Pennsylvania and administered to individuals along with the Temple Behavior Development Survey (Temple BDS). The two instruments would then be correlated with one another.

Through the endorsement of this project by the Commonwealth of Pennsylvania's Office of Mental Retardation, the Study Team received access to individuals living in a large, publicly operated ICF/MR. In addition, through the cooperation of a private ICF/MR provider in Pennsylvania, the study team was given access to individuals living in a large, private ICF/MR and to individuals living in several small ICFs/MR. The study team felt it was important to collect information in a variety of settings. The Temple BDS was collected along with the Colorado instrument (COPAR) and the New York instrument for approximately 30 individuals; 10 in each type of setting.

For states where training requirements are extensive and time spent is long, the Temple (BDS) was exported to the states, where trained data collectors collected Temple BDS in states where their own outcome assessments have already been completed. This occurred in both Massachusetts and Missouri. With the help of the states involved, HSRI and the University Affiliated Program in Missouri, Temple identified data

collectors and provided training to them by phone. For AC and CARF the study team pursued the possibility of collecting Temple BDS data in agencies that have received accreditation with the organization's outcome measures. Both accrediting bodies shared with the Study Team a listing of the facilities across the country that had received accreditation using the outcome standards. The Study Team then identified those facilities that were located in the area surrounding Philadelphia, or located in areas where there was a pool of trained data collectors (e.g., Missouri and Massachusetts). Agencies were contacted and from the contacts made we were able to complete data collection for 30 individuals supported by an AC-accredited agency and 30 individuals supported by a CARF-accredited facility. Both of the national accrediting organizations have been extremely helpful during this project, both in facilitating a member of the Study Team's participation in an accreditation review and in helping the Study Team complete the concurrent validity portion of the study.

Temple has conducted concurrent validity studies for Colorado, Massachusetts, Missouri, New York, AC and CARF. Oregon has completed its own concurrent validity study and its results are summarized in the state summary. In Utah, an "informal" study was conducted, where staff from Utah went to Colorado to apply the Outcomes Instruments to sites in Colorado.

In Oklahoma, a concurrent validity study was deemed unnecessary, as the Study Team was involved in the development of the Oklahoma instrument, which includes most of the scales that are being utilized in the Temple BDS. The Temple BDS has been tested for reliability and its coefficients have been found to be within acceptable ranges. Therefore, it is unnecessary to repeat the reliability studies.

### *Applicability*

The purpose of this portion of the analysis is to determine the extent to which the instruments can be used in a variety of settings, and for people with the most severe disabilities. In several states the outcome instruments that have been developed are applied across all residential settings. However, in some states the instrument is only used with a subgroup of the population, such as in Colorado where the COPAR is only used in agencies that contract with the Community Centered Boards; therefore ICFs/MR are not included. In Utah the Outcome Survey is only used in HCB Waiver programs or programs that are 100% state funded; therefore Utah does not use the instrument in ICFs/MR or in settings where the most capable people live (ICAP scores of level 1 or 2).

For those instruments that are only used with a subgroup of the population, the instruments were applied in a large, state-operated and a large, privately-operated



ICF/MR in Pennsylvania, where feasible. Most of the individuals in those settings experience severe or profound mental retardation, many use wheelchairs and many do not communicate in traditional ways. In those states where applying the outcome instrument requires extensive time or training, the instruments were not brought to Pennsylvania. Wherever possible, anecdotal data were collected, indicating whether the instrument is being used with individuals with the most significant disabilities.

In Oklahoma and with CARF, the outcome instruments are used in large, public ICFs/MR, places where individuals with the most severe disabilities often live. In Massachusetts, their outcome instrument (the QUEST) has been pilot tested in a large, public ICF/MR. As one would expect, the data show that the instrument can be used, but the scores in areas such as community inclusion are significantly lower than in most community settings. Instruments have been tested by the Study Team for applicability using the Colorado instrument (both in Pennsylvania and in an ICF/MR in Colorado) and the New York instrument.

The Missouri instrument is used only in the HCB waiver program, and because of the length of time it takes to administer and the data collector training requirements, was not collected by the Study Team. In Utah, the outcomes instrument is used only in waiver or wholly state-funded programs. This is partially due to the fact that the DD program office has no jurisdiction over the ICF/MR program. In addition, because of its perceived intrusiveness, the instrument is not used in settings that support individuals with the most mild disabilities (defined as ICAP level 1 or 2). Because of the training requirements and length of its survey process AC was not tested for applicability. Thus far, the largest facility receiving accreditation utilizing AC is a facility supporting close to 200 individuals.

The Oregon instrument (Residential Outcome System (ROS)) is used only in community settings. However, parts of the ROS have been used by one of the two large ICFs/MRs; it is not perceived as applicable in total in such facilities. However, in collecting health and safety data in Oregon, the study team collected data in a home where people lived who have significant medical complexities.

### ***Discriminant Validity***

This portion of the study determines the extent to which the instruments are successfully able to discriminate between individuals such that their scores on the outcomes are reflective of where they live, for example. In order to perform this part of the study, no original data collection was needed. However, the study team did need access to the data that have been collected on the quality outcome measures in each of the states. For the most part, this effort went smoothly; however, need for consent to

release information was a lengthy process in some states. In a few states the data that have been collected have been collected in long hand only, and had to be entered onto the computer system at Temple.

Data were received and analyzed for Colorado, Massachusetts, Missouri, Oklahoma, Oregon and Utah. In Massachusetts and Missouri data are collected at the facility level only; therefore analyses will be performed on a smaller data set than in states where data are maintained for individuals. New York had very little data, so the data collected for the reliability and concurrent validity portions of the study were used for the discriminant validity portion of the study. Again, detailed results are included in Appendix C.

### *Health And Safety*

In addition to the aforementioned statistical properties, HCFA has required that "the contractor shall identify the degree to which the outcome of protection of beneficiary health and safety, is present in each system." In order to respond to that issue, Temple developed a Health and Safety Issues instrument. The instrument includes information about medications, unusual incidents, behavior programs and safety within the residential setting. The instrument was collected in each of the seven states for a sample of at least 30 individuals, most of whom had outcome data collected about them, the program in which they live, or the agency from whom they receive services. Interviews were typically conducted with direct care staff who knew the individuals well; however, whenever possible, individuals receiving services and supports were invited and encouraged to participate in the interviews.

In order to compare the Health and Safety data collected by the Study Team to other Health and Safety data sources, a series of scales were created. The first scale is called the **Medication Scale**. One point was given for each of the following situations:

- The individual receives 5 or more medications;
- The individual receives medication for behavior control;
- The individual receives medication for behavior control but a continuing need for the medication has not been certified by the prescribing physician;
- The individual receives medication for behavior control but there has been no assessment of side effects;
- The individual receives medication for behavior control and has side effects;



- The individual receives medication for behavior control and has no psychiatric diagnosis;
- The individual receives medication for behavior control and has no behavior plan that includes the reduction of medication.

The **Medication Scale** has a range of 0 to 7, with a 7 indicating significant problems in that area.

The next area examined is the total number of doctor's visits during the past year. Respondents were asked to count the number of visits to general practitioners, gynecologists, psychiatrists, dentists, podiatrists and any other doctors the individual has seen during the past year. Respondents were asked to verify visits in the individual's record.

The next scale calculated from the Temple Health and Safety instrument is called the **Behavior Plan Scale**. The scale is comprised of the following items, where 1 point is given where each situation occurs:

- Evidence of physical restraints;
- Evidence of restraints that are **not** part of a program plan;
- Evidence of a time out room;
- Evidence of a time out room that is not part of a behavior plan;
- Evidence of the use of painful or noxious stimuli;
- Evidence of the use of painful or noxious stimuli that is not part of a program plan; and,
- There were unusual incidents that were not reported.

The scale ranges from 0 to 7, with a 0 indicating no issues in the area of the **Behavior Plan Scale** and a 7 indicating serious problems in the area.

The **Safety Scale** was created, using the following 10 items, where 1 point was given for each occurrence:

- Inadequate number of smoke detectors;

- Not all smoke detectors work;
- Not all fire extinguishers are charged;
- There was no fire drill in the previous 60 days;
- There was no fire drill in the 60 days prior to that;
- The home or living area is not clean;
- There are unpleasant odors in the home or living area;
- There are physical hazards in the home or living area;
- The individual does not have all prescribed adaptive equipment; and
- Not all living/program areas are accessible.

The scale ranges from 0 to 10, with a 0 indicating no problems in the area of safety and a 10 indicating significant problems in that area.

Last, the Study Team examined the issue of neighborhood safety. One item was collected assessing neighborhood safety. The item asked, how safe is this neighborhood? Possible responses were:

- |   |                         |
|---|-------------------------|
| 0 | Extremely safe          |
| 1 | Safe                    |
| 2 | Neither safe nor unsafe |
| 3 | Unsafe                  |
| 4 | Extremely unsafe        |

Safety is a quite subjective dimension. Hence, it was decided to leave its definition and interpretation to the respondent, rather than to the data collector who, not having experience in the specific geographic location, may define safety differently from the respondent who is more likely to know the neighborhood well.

In addition to collecting primary source health and safety data, Temple staff requested and have received other data with which the health and safety data have been compared including: outcome data, licensing data, Onsite Survey and Certification Automated Reporting (OSCAR) data (for ICFs/MR) and any other quality assurance data collected by the state on an ongoing basis. The purpose for gathering these data is to determine the extent to which states' quality assurance systems capture information regarding beneficiary health and safety.

For those facilities that carried the ICF/MR designation, results of the ICF/MR survey were entered onto a computer system that can then be accessed by states and by the federal regions. The data are presented in a variety of standardized formats that include data such as deficiency history, which lists the standards for which the facility was deficient over a period of several years, number of deficiencies by category, and so forth. These data are produced in reports titled Onsite Survey and Certification Automated Reports (OSCAR). For the states where ICFs/MR were reviewed for purposes of the health and safety data collection, states were requested to provide copies of the OSCAR3 and OSCAR4 reports. Where states were unable or unfamiliar with the OSCAR reports, assistance was requested and obtained from the HCFA Regional Office.

The OSCAR reports that were requested include a section which gives an analysis of the most recent ICF/MR survey by deficiency. The deficiencies are grouped by categories that include: Conditions of Participation, Standards (which includes most of the programmatic areas) and Life Safety Code. For each of the categories, the actual number of deficiencies is recorded for the facility. A table is included to show the average number of deficiencies in each of the areas for the state, the region, and the nation.

After consultation with HCFA staff, the study team decided to use the nation as the area for comparative purposes, due to the perceived possibility of state or regional idiosyncrasies. The study team developed a scale to rate each of the categories of deficiencies. The scale is as follows:

- 1 = Much Worse - the facility had more than two deficiencies more than the national average
- 2 = Somewhat Worse - the facility had more deficiencies than the national average
- 3 = Same - the facility had the same number of deficiencies as the national average
- 4 = Somewhat Better - the facility had fewer deficiencies than the national average
- 5 = Much Better - the facility had more than two deficiencies fewer than the national average

These scales (designated 01, 02, and 03) were compared with the states' health and safety, quality outcome and health and safety data that were collected by the study



team. For Scale 01 (Conditions) the national average is 0.06 deficiencies. For Scale 02 (Standards) the national average is 4.61 deficiencies. Lastly, for Scale 03 (Life Safety Code) the national average is 6.06.

A total of 248 Health and Safety Issues surveys were completed on site in the eight states by Temple staff. While our intent was to do 30 Health and Safety Surveys in each state, ultimately the number of surveys completed varied slightly by state. The number of surveys completed by state were as follows:

State   # interviews

CO	35
MA	30
MO	30
NY	30
OK	30
OR	31
UT	30
WY	32
Total	248

The types of residential settings visited by the data collectors varied by state. It was the Study Team's intent to include a sampling of as many of the different residential options as possible. However, given the limited amount of time spent in each state by the Study Team, not all residential placement types were represented. No small ICFs/MR were included in the data collection for a variety of reasons. In some states (Massachusetts and Missouri) the quality assurance systems are not implemented as part of the ICF/MR program. In other states (Colorado, New York and Oklahoma) most of the small ICF/MR programs are being converted to the HCBW; therefore, there were too few people from whom to choose. Neither Utah nor Oregon participates in the small ICF/MR program in the community. ICF/MR (16+ beds) were included in Colorado, Massachusetts, Oklahoma and Utah. The breakdown of residential types visited (by state) is as follows:

**Table 1-1  
Residential Settings by State**

<b>STATE</b>	<b>ICF/MR 16+</b>	<b>Group Home</b>	<b>Supported Living</b>	<b>Foster Family</b>	<b>Family/ Own Home</b>
CO	40%	57%	3%	-	-
MA	30%	70%	-	-	-
MO	-	97%	-	-	3%
NY	-	100%	-	-	-
OK	60%	40%	-	-	-
OR	-	100%	-	-	-
UT	33%	67%	-	-	-

The level of mental retardation was gleaned from the records as part of the data collection. The breakdown by state is as follows:

**Table 1-2**  
**Level of Mental Retardation by State**

STATE	Mild	Moderate	Severe	Profound
CO	14%	20%	34%	32%
MA	30%	20%	30%	20%
MO	36%	23%	37%	3%
NY	17%	13%	23%	47%
OK	40%	13%	20%	27%
OR	33%	27%	10%	30%
UT	30%	20%	37%	13%
Overall/ ICF/MR	15%	15%	22%	48%

As the table shows, in some states the sample included more people with mild retardation (Oklahoma and Missouri). In other states, the sample included more people with profound retardation (New York).

One of the questions asked regarding medical status was, "In general, how urgent is this person's need for medical care?" The possible responses were: Would not survive without 24-hour medical care; Has life-threatening condition that requires very rapid access to medical care; Needs visiting nurse and/or regular visits to the doctor; and Generally has no serious medical needs. The responses by state were as follows:

**Table 1-3**  
**Medical Needs by State**

STATE	Needs 24 -hour care	Needs Rapid Access	Regular Visits to Doctor	No Serious Needs
CO	0%	6%	26%	68%
MA	0%	3%	37%	60%
MO	0%	0%	20%	80%
NY	0%	3%	23%	73%
OK	0%	13%	3%	83%
OR	10%	0%	51%	39%
UT	0%	7%	37%	56%

As the table demonstrates, most of the individuals in the survey have no serious medical needs. Interestingly, only individuals in Oregon were reported as needing 24-hour medical care. Those individuals are currently living in community settings. No one that was surveyed who is living in a large facility was judged to need 24-hour medical care.

**Objective 4: To identify and review empirical studies of outcome-focused quality assurance systems,**

A literature search was conducted using four data bases: PsychINFO, Educational Resources Information Center (ERIC), NTIS and Health Planning and Administration. Relevant studies were obtained and reviewed. In addition to published research on outcome studies, unpublished studies were obtained.



The project team undertook two activities to identify the efforts nationwide examining "quality of life" outcomes for individuals with developmental disabilities along some or all of the following domains: self-determination, dignity, health and safety, consumer satisfaction, individualism, personal growth, community integration/inclusion, and/or social relationships. These activities were:

1. A comprehensive literature search using CDP On-Line which includes more than 120 databases including PsycINFO, Educational Resources Information Center, National Technical Information Center, and Health Planning and Administration;
2. The collection of unpublished empirical studies of quality outcomes, conducted by individual states and/or research organizations.

Presented here are the project team's findings from these efforts, followed by a summary and examination of the findings, and their implications for future quality of life evaluations.

### *Literature Search*

A comprehensive on-line literature search was completed to identify empirical studies of quality of life outcomes completed within the past ten years. The following four databases were searched:

1. PsycINFO (PSYC), which covers the professional and academic worldwide literature of psychology and related fields, includes 1300 journals, book chapters and books, contains about one million citations, dating back to 1967;
2. Educational Resources Information Center (ERIC), the largest educational database in the world, contains over 800,000 citations, dating back to 1966;
3. National Technical Information Database (NTIS), the major resource for locating U>S>; Government sponsored research reports in physical, health, social, and life sciences, contains 1;6 million documents, from 1970 to the present;
4. Health Planning & Administration (HLTH), an information resource for medical and health care professionals, covers worldwide literature concerning health care planning, organization, financing, management, manpower, and related subjects, from 1975 to present;



Terms used during the search included: disabilities (mental retardation, developmental disabilities), studies (empirical, quantitative), and quality (outcomes, quality of life, quality assurance, quality enhancement, independent living, deinstitutionalization). In this effort, however, the project team found very little "new" information. In fact, most of the Quality Assurance literature was written by people who are either project staff or members of the Technical Working Group. No "new" Quality Assurance systems (i.e. ones we did not already know about) were identified in the literature search.

### *Published And Unpublished Empirical Studies Of Quality Outcomes*

Through discussions with state administrators, researchers, and members of the project's Technical Working Group, several states were identified as participating, to some extent, in evaluation efforts using quality of life outcomes as a standard of measure. To some extent, these discussions assisted in the determination of which states participated in the project's site visit activities, and many of the materials collected were gathered during site visits to these states.

Data, reports, and sometimes, analyses of results from these evaluation efforts were collected from the states of Wyoming, Oklahoma, Oregon, Utah, Pennsylvania, and Colorado. Additionally, a recent study completed by The Accreditation Council for HCFA, analyzing national data collected during the ACD's Quality Review and accreditation process, was obtained. An earlier anticipated evaluation of the 1115 demonstration in Minnesota, using outcome-focused regulations and monitoring in ICFs/MR and Waiver homes, has been delayed and results are not yet available.

On the topic of quality of life, the bulk of existing literature revolves around: 1) why it is important to look at quality of life issues; 2) redirecting current quality assurance efforts to focus on quality of life outcomes; 3) defining "quality of life"; and 4) developing and analyzing methods of measurement. Indeed, very little has been written summarizing or analyzing empirical quality outcome studies for people with developmental disabilities. Most information in this area exists only in unpublished articles, and is available primarily through state disability agencies.

What follows below is an overview of the materials identified through this project's activities, and their efforts to measure, report, and analyze results of local quality of life outcome studies.

- Pennsylvania -- *The Pennhurst Longitudinal Study* (Conroy & Bradley, 1985), a five-year analysis of the impact of relocating people with developmental disabilities into the community, is considered the bellwether of quality outcome studies and has been used as a foundation by other states redesigning their quality assurance efforts. The primary areas of consideration for this

evaluation were skill & behavioral development, consumer satisfaction, qualities of environments (physical comfort, 18 aspects of normalization, individualization, life safety, encouragement of autonomy and activity, size and staffing patterns), family impacts, and costs. Comparisons were made between those individuals remaining in Pennhurst and those relocating to the community. Since the original study, data continues to be collected and reported annually for individual counties.

- Oklahoma -- *The Longitudinal Assessment of Consumer Outcomes* (Murray, Conroy & Ervin, 1994) summarizes an evaluation of consumer outcomes in the areas of independence (adaptive behavior), productivity (participation in activities that are useful and fulfilling), integration (opportunities to socialize with general population), and satisfaction. Comparisons by characteristics of consumer and residential setting (public ICFs/MR, private ICFs/MR, nursing facilities, group homes, supported living, and community placements) were conducted. The study was found to yield generally reliable results, except for the physical quality scale and site impression scale (which were considered highly subjective).
- Colorado -- *A Report on Outcomes of Services and Supports for Persons with Developmental Disabilities* (Ruth & Struxness, 1994) summarizes and analyzes the results of ongoing use of the COPAR (Colorado Progress Assessment Review) instrument. This evaluative tool focuses on consumer satisfaction with services, decision-making, community inclusion, community integrated employment, talents and personal goals, relationships and a sense of belonging, personal security, self-respect. These issues directly correspond to legislative language pertaining to outcomes for people with developmental disabilities. In 1992-93, the COPAR was administered to 781 adults with disabilities, and 1000 adults in the general Colorado population. Comparisons of results were conducted along four basic themes: 1) comparison of outcomes across various service approaches (institutional setting, community group settings, community individualized settings); 2) comparison of actual service performance (all residential service participants) against a performance target (general population); 3) comparison of outcomes longitudinally to see if there are system-wide improvements in outcomes across time; and 4) comparison of outcomes by characteristics of people in services (demographics, support needs). Tests for reliability/statistical significance were conducted.
- Utah -- Utah annually collects and reports data from their statewide quality assurance efforts. *The 1995 Consumer Report on Home and Community Based Services* (Division of Services for People with Disabilities, 1995) summarizes outcome surveys yielding scores on four standards: 1) opportunities for personal growth and development; 2) facilitation of individualization and full participation; 3) community integration (opportunities to live, work and



associate with others in the community); and 4) use of a provider quality assurance system. The report also includes results of consumer satisfaction surveys (satisfaction with service provider) in the areas of day training, supported employment, residential services, supported living, family support and the professional parent program; as well as results from volunteer monitoring visits.

- Oregon -- *Focusing on Values and Lifestyle Outcomes in an Effort to Improve the Quality of Residential Services in Oregon* (Newton, Ard, Horner & Toews 1996) details efforts to assess the physical integration, independence, and social integration of individuals with developmental disabilities residing in Oregon's community residential settings. Also addressed are individual's frequency and variety of activities, and participation in preferred activities. Reporting of results centers on these latter activity levels.
- Wyoming -- Evaluation efforts in Wyoming are illustrated in *Changing the Shape of the Service Population* (Fortune, Heinlein & Fortune, 1995), where the ICAP (Inventory for Client and Agency Planning) was used to evaluate adaptive behavior (social and communication, personal living, community living, and motor) and maladaptive behavior (internalized, externalized, and asocial) of people with developmental disabilities residing in the state institution and community settings. The study period included years 1988 through 1994, and compared individuals residing in institutions, with those living in the community and those transitioning from institutional to community life. Over the years noted, this study examined changes in the distribution of ICAP scores in the population served, and changes in individual's adaptive and maladaptive behavior scores.
- The Accreditation Council -- *The Quality Assurance Measures Database: Final Report* (ACD, 1995) provides an overview of results and analysis from interviews conducted with 440 individuals with disabilities receiving services from 54 organizations across the country. These interviews focused on the progress toward or achievement of 30 specific "outcomes for people", that fell into these categories: personal goals, choice, social inclusion, relationships, rights, dignity and respect, health, environment, security, and satisfaction. Comparisons of results were examined by type of residential setting, funding (e.g., ICF/MR, HCBW), level of disability (e.g., mild, moderate, severe/profound mental retardation), services and support received, organization size, and geographic characteristics (e.g., urban, rural, suburban).
- Pennsylvania -- *The Small ICF/MR Program: Dimensions of Quality and Cost* (Conroy, 1996), compares quality of life dimensions for 51 people living in small ICFs/MR with those for an equal number of individuals living in community living arrangements (CLAs). Data for this analysis was collected

between 1988 and 1992, using 49 indicators of quality for comparison (e.g., choicemaking, productivity, home environment, health and health care, integration, behavioral progress).

**Objective 5: To analyze application of the current ICF/MR active treatment definition and its consistency with current concepts of support.**

In order to make determinations about those aspects of HCFA's regulatory definition of active treatment and interpretive guidelines, HSRI used several sources of information in conducting the review:

- Informal discussions with State contacts across the nation regarding their experience with ICF/MR quality assurance and perspectives on the active treatment regulations and guidelines, in conjunction with the inquiries done for the development of the Task A Interim Report;
- Interviews with knowledgeable individuals during the State site visits conducted to review outcome-focused quality assurance systems;
- Review of the literature on ICF/MR quality assurance;
- Input from members of the Technical Working Group and their respective organizations, as appropriate;
- Interviews with ICF/MR providers around the country;
- Review of HCFA's Draft Revisions to the Survey Process for ICFs/MR.

In consultation with the HCFA project director, project staff substituted a case study approach for the observation of an ICF/MR survey. The case studies of active treatment are targeted to five issues: promotion of best practice, continuous active treatment, overprogramming, choice, and conflicts with outcome-based approaches.

**Objective 6: To identify implications for changes in the current ICF/MR quality assurance system.**

The results of all of the above activities conducted as part of Task A as well as feedback from the Technical Working Group and HCFA were reviewed in order to identify implications for changes in the current ICF/MR quality assurance system.



### **III. RESULTS AND FINDINGS**

#### **Objective 1: Summary of Outcome Focused-Quality Assurance Approaches**

##### **The Degree Of Quality Assurance Reform**

Quality assurance systems are in a period of transition in most of the states, each at various stages of reform. Overall, there is a clear trend toward outcome-focused quality assurance systems.

Three categories were developed to characterize the degree to which quality assurance reform approaches an outcome-focused system, as well as two "transition" categories. The need for the "transition" categories became apparent in the discussions with the States, reflecting both the strong interest in quality assurance reform and the current fluidity of quality assurance nationally. A total of 29 States also reported that they were projecting changes in the next year (i.e., 1995-1996). As noted above, all but 12 States are actively moving toward an outcome-focused quality assurance system and State officials in six of these States expressed interest in increasing their focus on outcomes.

The categories and number of States in each category as of spring 1995 are as follows:

##### **Category I: Significant movement toward outcome-focused quality assurance: (10 States)**

This category includes States that may not have completely eliminated traditional quality assurance, comprehensive licensure and certification (L&C) surveys, etc., but include definitive outcome focus and systems include the primary outcomes of interest. These States may not have included all settings (e.g. their ICFs/MR and state institutions), but are using outcome-focused quality assurance in settings serving individuals with the same characteristics (e.g., severe and profound mental retardation, complex disabilities).

##### **Transition II to I: States actively in transition to an outcome-focused system: (12 States)**

This category includes States that have made the decision to reform their quality assurance systems to an outcome-focused system, and the reform is underway. For example, some States in this category are conducting a demonstration to determine how to implement such a system.

**Category II: Some reform aimed at outcome-focused quality assurance including the primary outcomes of interest (9 States)**

States in this category may be applying the primary outcomes in some form of a demonstration project, such as a pilot in one part of the State that may become the future model, or an outcome-focused quality enhancement program such as citizen monitoring, or an outcome-focused quality assurance that applies only to one type of residential services (for example, supported living - if possible, however, one that includes at least some individuals with same characteristics as ICF/MR residents.) These States continue to rely on traditional licensure and certification process.

**Transition III to II: Beginning the process of developing some aspects of an outcome-focused quality assurance system: (5 States)**

States in this category are actively planning a pilot project, may have a task force that has recently issued its first report, new legislation that will require them to move ahead with reform, but are not committed, as yet, to comprehensive quality assurance reform focused on outcomes.

**Category III: Little or no movement toward outcome-focused quality assurance reforms: (12 States)**

These States may have a task force beginning to address the issues, a pilot that is no longer operative, some token activities focused on quality of life measures, but are still relying primarily on traditional quality assurance.

**Other: (3 States)**

In this category are States with deemed status provisions (CARF and/or Accreditation Council) [2 States] and one that is moving from Category I to Category II.

Table IV 1 illustrates the category of quality assurance reform for each State.

**TABLE 2-4**  
**CATEGORY OF QUALITY ASSURANCE REFORM**

State	I	II>>>I	II	III>>>II	III	Other
AL				X		
AK	X					
AZ			X			
AR		X				
CA		X				
CO	X					
CT			X			
DE					X	
FL		X				
GA		X				
HI					X	
ID					X	
IL			X			
IN					X	
IA		X				
KS				X		
KY		X				
LA					X	
ME	X					
MD					X	
MA	X					
MI					X	
MN			X			
MS					X	
MO		X				



TABLE 1-4 (CONTINUED)

State	I	II>>>I	II	III>>>II	III	Other
MT						X
NE			X			
NV				X		
NH			X			
NJ					X	
NM			X			
NY		X				
NC				X		
ND		X				
OH						X
OK	X					
OR	X					
PA			X			
RI		X				
SC				X		
SD						X
TN	X					
TX		X				
UT	X					
VT	X					
VA					X	
WA			X			
WV					X	
WI	X					
WY		X				
DC					X	
TOTAL	10	12	9	5	12	3



## **Scope Of Facilities/Residential Services And Populations Covered**

At least 19 States with outcome-focused quality assurance systems apply measures to agencies serving significant numbers of individuals with the same characteristics as ICF/MR residents (severe or profound levels of mental retardation and multiple disabilities).

All but five States that are using outcome-focused quality assurance approaches in a systematic fashion exclude ICFs/MR from the process primarily because of the traditional separation between ICF/MR quality assurance and non-ICF/MR quality assurance. As illustrated in IV 2, however, some States do include ICFs/MR in their quality assurance activities:



**TABLE 1-6**  
**SCOPE OF RESIDENTIAL SERVICES AND POPULATIONS COVERED**

State	Scope of Residential Services Covered	Coverage of Individuals with Same Characteristics as ICF/MR Residents	Additional Comments
AK	All but ICFs/MR (one small State facility and five small private ICFs/MR)	Yes	
CO	Includes State institutions (ICFs/MR) but not community ICFs/MR except indirectly; adults only	Yes	Because COPAR survey includes sample of community day program participants, some community ICF/MR residents included as well as State institution residents
FL	Pilot demo in one State HRS District; includes HCB waiver but no ICFs/MR	Similar functioning level, however, ICFs/MR serve those who are medically fragile	
ME	All community residences	Yes	
MA	All community residences, including many HCB waiver (State has no community ICFs/MR); using in State institutions for quality enhancement and piloted QUEST in State institution	Yes	
MN	Demonstration project with 5 ICF/MR providers in 5 counties	Yes, although community ICFs/MR may serve somewhat less severe/complex disabilities than State institutions	Participating agencies will apply the new quality assurance to 150 ICF/MR residents + an additional 300 in HCB or Supported Independent Living services

TABLE 1-6 CONTINUED

MO	Primary focus on HCB waiver services	Yes	
NH	All community residences (NH has no State institution)	Yes	Mixed
NY	COMPASS demonstration project with 24 OMRDD-licensed community residential service agencies/1,000 individuals, including both State- and privately-operated. A few ICF/MR and HCB waiver beneficiaries included indirectly.	Yes - 24 percent with severe MR, 7 percent with profound MR; also 14 percent with physical disabilities and/or "wheelchair dependent"	State plans to apply for demonstration of COMPASS in community ICFs/MR and to extend to HCB waiver services in the near future
OH	All, including State institutions	Yes	
OK	All community residential services; longitudinal outcome data also being collected in State institutions	Yes	
OR	All except State institutions, however, they use for QE	Yes	OR-AIM (citizen monitoring focused on outcomes, quality of life) required for people moving from State institution to community
RI	All, including State institutions	Yes	
TN	All except ICFs/MR	Yes	
UT	All except ICFs/MR	Yes	
VT	All community residences	Yes	



TABLE 1-6 CONTINUED

WI	HCB waiver services	Yes	Targeted especially to individuals who have moved from State institution to community residences
WA	All except ICFs/MR	Yes - 500 of the 900 people who have moved from the State institution and whose outcomes are monitored are individuals with either severe or profound mental retardation.	
WY	All except the State institution (no other ICFs/MR)	Yes	

## Selection Of Quality Outcomes

The project survey shows that States that have moved toward an outcome-focused quality assurance system and have defined important outcomes as part of that effort have selected outcomes that are remarkably consistent with those selected by HCFA and the Technical Working Group (the primary outcomes). The States with all eight primary outcomes are illustrated in Table IV 3.

**Table 1-7**  
**Selection of Primary Outcomes**

<b>Primary Outcome</b>	<b>Number of States</b>	<b>How primary outcome Typically Defined</b>
Individualization	30	Services based on individual choices, preferences, needs - primary emphasis on choice (22 of the 30)
Integration/Inclusion	29	Community presence, participation, membership; social inclusion
Relationships/Social Connections	26	Relationships with friends and family
Health and Safety	25	Health and safety; well-being; personal security
Personal Growth	25	Various - personal growth, competence, attainment of individual goals, skill acquisition
Self-determination	25	Various - control, choice-making, decision-making, power, independence
Dignity	24	People treated with respect and dignity; age-appropriate services (some)
Consumer Satisfaction	19	Consumer satisfaction

Other observations include:

- The majority of state quality assurance systems do not include a database on the primary outcomes of quality;
- Decreasing focus on document review with a corresponding increasing focus on observation and interviews, in particular increased contact with service recipients;
- Continuing use of process measures in outcome-focused quality assurance reviews, but with greater emphasis on processes that are seen as directly tied to specific primary outcomes;
- A mixed picture as to how much "traditional" quality assurance is being retained as primary outcomes, in particular those associated with quality of life;
- General trend toward reduction of prescriptive rules and standards and development of streamlined licensure and certification procedures;
- Increased focus on individuals, their satisfaction, and choices, as well as an emerging approach with individuals as the organizing principle of the quality assurance system, (and the service system) rather than provider agencies;
- Consensus on quality assurance reform growing among stakeholders in most States, and recognition of the importance of involving stakeholders in developing and building consensus on outcome-focused quality assurance systems;
- Emerging trends: increased decentralization of quality assurance activities, tying quality assurance reforms to managed care and using cross-disability quality indicators.

Overall, there is strong interest and support for outcome-focused quality assurance systems in residential services, for individuals at all levels of mental retardation/developmental disability, and in all settings. The above findings were mirrored in the eight case study states.





## **Objective 2: State Approaches to Outcome-Focused Quality Assurance in Selected States**

### **Overview**

The seven study states employ similar arrays of outcome-focused quality assurance mechanisms, but all have evolved into somewhat unique mechanisms. This section begins by explaining the service system context in each state, in particular how quality assurance is managed. It then identifies the major tools and processes the states are using to assess consumer outcomes, and discusses the relative merits of each type of approach. Common themes are then presented, in the evolution of the outcome-focused systems and the challenges to their implementation. Finally, the states are compared on their commitment to outcomes, the breadth of their use of the outcome-oriented tools, and their use of the outcome information.

The ensuing analysis is based on a review of relevant quality assurance materials in each state as well as key informant interviews in each state (a list of those interviewed is included in Appendix E).

It is important to note that as these QA reforms have been occurring, states have simultaneously been faced with other -- sometimes countervailing -- pressures for change. All states are experiencing budgetary uncertainties, and many feeling immediate pressures to adopt a Managed Care approach to contain costs and transfer decision-making and risk to local levels. Colorado has put forth a "Blueprint for Change," laying out a possible plan for greater decentralized authority to the Community-Centered Boards; Oklahoma has a Governor's Performance Team that has just completed a study of all departments, identifying ways to reduce service costs. Massachusetts is facing both of these pressures, in the Governor's plan to restructure state government including a move to reliance on managed care organizations. These challenges, coupled with growing waiting lists, will continue to strain that ability of states ability to develop and maintain high quality community residential arrangements.

### **State Systems**

Five of the seven states examined in this study place responsibility for developmental disabilities services at or below the divisional level in state government. In Missouri, the Division of Mental Retardation and Developmental Disabilities (DMRDD) is located within the Department of Mental Health; in Oklahoma, the Developmental Disabilities Services Division (DDSD) is within the Department of Human Services; and in Utah, the Division of Services for People with Disabilities (DSPD) lies within the Department of Human Services. In Oregon and Colorado, responsibility sits one level lower -- Colorado's Developmental Disabilities Services (DDS) is within the Office of Health and Rehabilitative Services in the Department of Human Services; in Oregon, the Office of Developmental Disabilities Services (ODDS) is located within the Mental Health and

Developmental Disabilities Services Division, under the umbrella Department of Human Resources. New York and Massachusetts have a separate department for developmental disabilities: Massachusetts' Department of Mental Retardation (DMR) and New York's Office of Mental Retardation and Developmental Disabilities (OMRDD) report directly to the governor. New York has the further distinction of being the only one of the study states which has a separate Division of Quality Assurance (DQA), within the OMRDD.

### **Service System Configuration**

It is helpful to understand the service system context in which quality assurance reform is taking place -- how many individuals are currently in what types of settings, and what degree of control the state DD offices have over those various residential arrangements -- in order to more fully understand the pressures states may feel as they downsize large ICFs/MR and struggle to maintain quality in increasingly diverse settings. Table V 1 shows distribution of consumers receiving residential services in each state, in terms of total numbers and percentage of the state's residential consumers (numbers are in some case approximations).

**Table 1-8**  
**STATE RESIDENTIAL SERVICES POPULATION, 1995**

STATE	Residential Consumers	ICF/MR Consumers	Public ICF/MR Consumers	Community-Based ICFs/MR Consumers	Consumers in Community Settings $\leq 3$	Consumers in Community Settings 4+
CO	4000	245 (6%)	175	70	2400 (60%)	1200 (30%)
MA	8800	1900 (22%)	1900	None	6900* (78%*)	6900* (78%*)
MO	6500	1516 (23%)	1329	187	3000 (46%)	2000 (31%)
NY	31219	8803 (28%)	494	8309	7315 (23%)	15101 (48%)
OK	4000	2375 (59%)	575	1700	975 (24%)	675 (17%)
OR	4000	470 (12%)	470	None	1000 (25%)	2500 (63%)
UT	2100	864 (41%)	359	505	800 (38%)	434 (21%)

The seven states vary significantly in the extent of their reliance on ICFs/MR, from minor usage in Colorado and Oregon to substantial reliance in Oklahoma and New York. Among community residential settings, all the states except Oregon utilize smaller settings (of three people or less) more frequently than they do the larger group-home settings, reflecting their commitment to more individualized living arrangements.



A critical factor affecting the size and the quality of the ICF/MR population in each state is where responsibility lies for ICF/MR facilities. All state DD offices administer their public institutions, except Colorado. Private ICFs/MR tend to be more independent. Of the five states that have such facilities, two DD offices do not have jurisdiction over the private system. In Utah and Oklahoma, the private ICFs/MR are under the jurisdiction of a separate department, thus governed by separate quality assurance standards. Key informants in these agencies were also interviewed. The only guaranteed oversight is the ICF/MR certification process, making that process thus even more important in moving ICFs/MR toward consumer outcomes.

### **Quality Assurance Capability**

The state DD offices have responsibility for assuring quality in the residential settings they administer; they also usually carry responsibility for state monitoring responsibilities, sometimes licensing authority (Oregon), and some amount of training and technical assistance capability (Oregon, Oklahoma, Utah, Wyoming). Staffing levels have influenced the range of tasks the DD office can shoulder -- Colorado's five Program Quality staff are no match for New York's surveyor staff of over 90 or Massachusetts' more than 50 QUEST staff, hence Colorado relies much more heavily on regional staff to monitor and on providers to self-evaluate.

### **Primary Outcome-Focused QA Mechanisms**

All the study states have one or more quality assurance mechanisms that assess the selected outcomes. Table 1-9 highlights the characteristics of these approaches.



**Table 1-9  
OUTCOME-FOCUSED QA MECHANISMS**

STATE	MECHANISM	YEAR BEGAN	PRIMARY RESPONSIBILITY	USED IN ICF/MR?	DESCRIPTION
CO	COPAR	1986	DDS, private firm	Yes	Longitudinal evaluation of service outcomes based on interviews with consumers and primary support staff
MA	QUEST	1993	DMR	No	Enhancement-oriented site survey focused on individual consumers
MO	Certification survey	Piloted 1995	DMRDD	No	Enhancement-oriented site survey by diverse team, focused on agency as a whole
	MOAIDD	Pre-pilot	MOAIDD	No	Citizen monitoring visits done in alternate years of certification survey
NY	COMPASS	Piloted 1993-94	DQA	Optional	Quality improvement system includes management planning, self-survey, and outcomes review
	CARE	1993	DD Council	No	On-site review of residential programs (observation and interviews) by consumers, families and advocates, in programs that volunteer
OK	QA Survey	1990	DDSD	No	On-site assessment of agency compliance with AC standards and DDSD contract standards, done by DDSD staff, including observation, interviewing, and records review
	OSU Consumer Assessment	1990	OSU	Yes	Longitudinal assessment of individual consumers, including interview with consumer and primary support person, and home observation
	AIM	1991	Tulsa ARC	No	Citizen monitoring of community residences done by local ARC parents and consumers, including interview and observation
OR	ROS	1994 (1985 VOIS)	ODDS, U of O	No	Individual-based outcome monitoring system, including assessment, service planning, and implementation, completed by direct care staff
	AIM	1991	Oregon ARC	No	Citizen monitoring of selected community residential settings done by local ARC volunteers (parents, consumers, and other citizens)
UT	QE Outcomes Survey	1991	DSPD	No	On-site assessment of agency compliance with outcome standards, based entirely on observation and interview of individual consumers
	Consumer survey	1995	DSPD	No	Consumer interview used as supplement to QE survey
	Volunteer Monitoring	1980 (USDC) 1990 (com)	MRAU initially, now DSPD	Yes	Citizen monitoring in all residential settings by parents, including observation, consumer interviews, and parent telephone interviews

Table 1-9 reveals that most of the study states have more than one outcomes-focused QA mechanism. The most common types of processes include *certification-type surveys*, in four states (more states have such surveys, but not all are strongly outcome-oriented); *consumer survey* approaches, in five states; and *citizen monitoring* efforts, in five states. One state, New York, has a comprehensive quality improvement system, although other states have less extensive QA techniques addressing the same issues. Most of these tools are not used in the ICF/MR facilities, and most are carried out by the state DD offices (citizen monitoring being the biggest exception). The outcomes focus is fairly new in all the states, with only COPAR and the ROS predecessor, VOIS, beginning prior to the 1990's.

The site visits revealed that the states have quite varied reliance on outcome-oriented QA tools. All the outcome tools are focused in some way on *improving outcomes of consumers*, and all assess *the process of reaching* the desired outcomes, but not all of them actually assess the *achievement* of the outcomes. For example, Utah's QA outcomes survey measures the extent to which "the individual is encouraged and assisted to have friends in the community with whom he/she does not reside," but it does not assess whether such friendships are formed;

Another important difference across the study states is the degree of commitment by the state DD office to promoting outcome-focused quality assurance as a preferred approach over more traditional regulatory compliance techniques. Several of the states have embraced outcome-oriented QA over any other approaches (e.g., Colorado, Oklahoma, and New York). By contrast, Oregon, while committing significant resources to outcome-focused QA, has not adjusted its licensing approach to support agencies exploring innovative ways to achieve consumer outcomes, and it has not expanded the use of AIM to all community residential settings.

### *Certification Surveys*

Several of the states have based their program survey processes on AC or CARF standards: Oklahoma currently uses AC process standards and Utah has borrowed heavily from ACD to build its outcomes survey. Other states have created their own outcome-oriented survey processes (Colorado, New York, Massachusetts) have modified their licensing standards accordingly. The Missouri and Massachusetts processes are very labor intensive -- Missouri's certification process can take from 2 days to 2 weeks to complete, QUEST from one week to ten weeks.



### *Self-assessment*

Self assessment is an alternative to state agency monitoring in only two states, Colorado and New York, and only for selected agencies (in New York, all COMPASS participants). Several of the other study states have self-assessment processes, but these do not substitute for an on-site visit by the state DD office team.

### *Deeming*

Deeming providers as meeting state standards when they receive national accreditation is a policy in only one state, Missouri. Oklahoma does recognize national accreditation, waiving the QA survey for agencies who are accredited by AC or CARF. Utah is encouraging providers to pursue AC accreditation, by supporting a Quality Assurance Consortium where agencies discuss their efforts toward accreditation.

### *Consumer Survey Approaches*

Several of the study states have developed consumer survey tools to assess consumer outcomes. University-based researchers in Colorado, Oklahoma, Oregon and Utah. The Oklahoma, Colorado, and Oregon tools are used longitudinally, and have been generating data for several years, providing an important resource for studying effectiveness. A key differentiating characteristic among the consumer survey instruments is where responsibility for measurement lies. An external entity conducts the surveys in Oklahoma and Colorado, and the Oklahoma survey is also analyzed and refined by the outside group (OSU); data-gathering is provider-based in Oregon and Wyoming, the latter allowing the providers to choose their own tool; only in Utah are the consumer surveys handled by DD office staff.

The consumer survey tools are generally used only in community residential settings, although Colorado's COPAR and Oklahoma's Longitudinal Survey are done with people in all settings. In nearly all the states, the public ICFs/MR are exploring ways to use a modified version of the state's consumer survey tool, so such practices will likely become more common in the future.

### *External Volunteer Monitoring*

Five of the study states use some form of external volunteer monitoring, Missouri, Oregon, Oklahoma, New York and Utah. The citizen monitoring approach, while considered valuable by key informants in the states visited, has received varying levels of financial and official support, and occupies a

somewhat precarious position in state QA systems. This is in part because of the difficulty in mounting a system that relies on volunteers, in part because of a lack of stable funding, and in part because of an ambivalence in these systems regarding the authority that should be vested in citizen reviews. The experience in these states suggests that to survive, citizen monitoring requires advocacy sponsorship, paid coordinating staff, a commitment to the importance of citizen monitoring, stable funding, and systematic training of volunteers.

### *Continuous Quality Improvement Mechanisms*

Focused attention to overall organizational improvement, as exemplified in continuous quality improvement efforts (CQI), varies considerably among the study states, although it is recognized as a crucial process in improving consumer outcomes, especially as quality assurance responsibilities are increasingly delegated to regional DD offices and to providers themselves. Missouri and New York have made the most dramatic commitment to CQI approaches and Missouri similarly puts organizational change at the heart of the state-sponsored certification process. Oregon also devotes specific resources to fostering organizational change, but such activities are not mandated. Other states do not address CQI per se, but have adopted much of the spirit of the CQI movement, making their QA surveys noticeably less punitive.

### *Health and Safety Safeguards*

All the study states have taken the movement toward consumer outcomes seriously, and have made modifications in their approaches to assuring basic health and safety, in community residences as well as in ICFs/MR. Like the changes in ICF/MR process, most of the study states' own minimal health and safety surveys have become less targeted on documentation and more focused on observation and interviews, both with staff/primary support person and consumers. This shift has not reduced attention to safeguarding health and safety; rather, it has made the efforts more clearly targeted on specific risk situations. Several states have added "Red Flag" checklists to other of their QA mechanisms (e.g. Oklahoma AIM, Utah's QE survey).

The incident reporting process appears to be a weak link in many states, with little oversight at the state level and varied attention given by local officials; and some states are swamped with insignificant incidents, making them unable to respond promptly and thoroughly to serious incidents, or to step back and identify underlying systemic problems (e.g. staff training, supervision, environment). New York is the exception, where DQA staff monitor quarterly trend reports from each local office, and follow up when unusual patterns appear.



With respect to the two accreditation mechanisms reviewed, the ACD *Performance Measures for Organizations* include health, safety and welfare measures. Within the CARF administrative review of the provider agency, "rights, health and safety" are combined as one of eight accreditation criteria for which the provider must show it has documented policies.

## **The States' Shift To Outcomes-Focused QA**

### ***Making the Shift: Impetus, Key Factors***

The common factors influencing the study states' shift toward outcome-focused quality assurance were: (a) lawsuits targeted at the large state institutions (Oklahoma, Oregon, Massachusetts, Utah, and Colorado); (b) leadership and vision in the state DD office (Colorado and Oklahoma), and (c) availability of new service monies through the HCBS waiver (Missouri). In the states selected, there was evidence of a growing consensus regarding the importance of having outcome-focused QA, and increasing attempts to involve all key stakeholders in collaborative efforts to direct QA and systems reforms.

Another key factor, cited by state officials in Oklahoma, was the a recognition of the evolutionary nature of the shift which had to proceed through the process-focused phase, as a foundation for a focus on outcomes..

### **Implementation Challenges**

The major challenge to the implementation of an outcome-focused quality assurance system is changing the attitudes and expectations of providers as well as surveyors who are still conditioned to regulatory compliance and professional decision-making. This was particularly true in Missouri, New York and Massachusetts. Thus, the process of instituting such a system must come to grips with organizational development issues in order to ensure a common understanding of the assumptions that underlie an outcome-based system.

Several expected challenges did not materialize as significant issues in the study states. One anticipated concern was that states, in their rush to outcomes, would lose control over basic health and safety. None of the states abandoned their focus on health and safety, but, rather, balanced it with the new/expanded look at consumer outcomes. Another expected problem was that states would lose the support of key stakeholders. To the contrary, state DD officials focused on keeping in good communication with the field; they included other stakeholders in planning and design efforts; and they lessened their punitive and prescriptive role (especially in Oklahoma and Colorado). A third anticipated difficulty was the role transition for QA surveyors.

## Aspects Of Outcomes-Focused QA

### Key Outcomes and Outcome Measures

Table 1-10 illustrates the distribution of the HCFA selected outcomes among the QA systems in the seven study states.

**Table 1-10**  
**HCFA SELECTED OUTCOMES IN STATE QA INSTRUMENTS**

QA Component HCFA Outcome	CO: COPAR	MA: QUEST	MO: Certification survey	MO: MOAIDD	NY: COMPASS	NY: CARE	OK: Consumer Assessment	OK: AIM	OR: ROS	OR: AIM	UT: QE & Consumer Satisfy. Survey
Self-determination	X	X	X	X	X	X	X	X	X	X	X
Dignity	X	X	X	X			X	X		X	
Health and Safety	X	X	X	X			X	X	X	X	X
Consumer Satisfaction	X		X	X	X		X	X	X	X	X
Individualism	X	X	X	X	X	X	X	X	X	X	X
Personal Growth	X	X	X	X		X	X	X		X	
Community Inclusion	X	X	X	X	X	X	X	X	X	X	X
Relationships/ Social Connections	X	X	X	X			X	X	X	X	X

The near-complete attention to the eight valued outcomes evident in Table 1-10 masks what appears to be distinct stages in the evolution of states' ability to focus clearly on consumer outcomes. Respondents in several states commented that one cannot look only at outcomes, but has to continue to attend to process. In states where the vision of systems reform and the commitment to an outcomes focus have been strong, and where a broad array of stakeholders share that vision and commitment (Colorado, Missouri, and Oklahoma), the move to outcomes appears to have been the steadiest -- fairly consistent across programs and over time. Where the state has pushed for change without the providers being fully willing partners (Oregon, Utah, and Massachusetts), one does not get



the same sense of a system-wide transformation to outcomes. These states still need to pay close attention to process, and especially to minimal standards of health and safety, because providers do not necessarily willingly make the change. Some observers may argue it has to do with the level of disability of people living in the community, but observation does not support that thesis. Wyoming stands alone in a different stage of evolution, where some of the providers have led the change, and now do not want the state to impose any mandates; the result is that DDD has no one outcome tool that has been used consistently over time or across providers, making it less able to assess overall system performance in an outcomes context. The imminent adoption of CARF's outcome standards may remedy that problem.

### **Applicability To Various Settings and Various Populations**

As a general rule, the DD offices in the study states have not applied their outcome-focused tools in ICF/MR facilities, usually because either the bulk of the ICFs/MR were not under the jurisdiction of the state DD office (Utah and Oklahoma), or the ICFs/MR were seen as appropriately and sufficiently regulated by HCFA. The states tended to give priority to designing QA mechanisms for settings where no other agency was providing oversight.

*People With the Most Severe Disabilities.* State quality assurance officials in the seven states see consumer-centered outcomes as being fully applicable to people with the most severe disabilities. In particular, these respondents emphasized that face-to-face interviewing with consumers is crucial for all consumers, especially in assessing the outcomes of satisfaction, social relationships, dignity, and choice. The only consistent reservation expressed concerned people with significant medical needs, the argument being that more careful attention to health and safety is necessary for this group of people.

Colorado and Oklahoma have made particular efforts to make their outcome-focused tools useful with people with the most severe communication difficulties, Oklahoma by using interviewers with sign language and receptive skills, as well as a picture book, and Colorado by revisions to the COPAR instrument. In addition, both states' consumer survey processes supplement the consumer information with information from primary support people. Oregon relies primarily on direct care staff to record the relevant information on an ongoing basis, with little direct consumer interviewing about outcomes.

New York quality assurance officials emphasize the need for special training for surveyors in applying the core outcomes to people with severe disabilities, especially assessing choice and satisfaction for people with severe communication disabilities; they currently make use of secondary respondents

(primary caregivers), and some agencies have trained surveyors to read non-verbal cues. Missouri, like Colorado and Oklahoma, has successfully interviewed individuals living in waiver-funded homes who have severe disabilities.

Quality assurance officials in New York also noted that outcome expectations may need to be somewhat different for people with severe disabilities, especially in the areas of friendships and choice-making. New York DQA staff highlighted the distinction between outcomes promoted and outcomes achieved: they felt it is was important to identify situations where the staff provided an environment which promoted the achievement of the outcomes but where the outcomes were not fully achieved due to the nature of the individual's disabilities or the choices he/she made. Utah has developed such a schema in its scoring of the QE survey indicators.

*Institutions and Community-Based ICFs/MR.* A consensus similar to that around consumers with varying levels of disability emerged in considering the applicability of outcomes to various types of residential settings. In general, the outcomes are seen by state quality assurance officials as being applicable to people living in ICFs/MR, although they were quick to acknowledge the differing potential for outcomes in different residential models (for example, Oklahoma's Assisted Living residents receive less supports and generally have less money; remote institutional campuses face considerably greater barriers to achieving community inclusion).

Active treatment is one area where the compatibility of the valued outcomes with current ICF/MR regulations is ambiguous. Utah's ICF/MR administrators do not see a conflict between active treatment and the outcomes standards. They see the former is the basics, the latter is more creative, and they say it is easy to marry the two, with active treatment as the foundation. They feel supported in this view by the HCFA regional office training they have received. In sharp contrast is Oregon's experience, where ICF/MR surveyors are having considerable difficulty seeing the institutions' efforts in person-centered planning as meeting active treatment requirements.

It appears that the potential problems with the applicability of outcome standards in an ICF/MR environment are more related to the routinized patterns and social isolation of the institution (the "culture"), rather than being inappropriate indicators for people with severe disabilities. This suggests that a precursor to implementing outcome-focused QA in the ICFs/MR should be extensive training and acculturation, among staff and surveyors alike.



Finally, with respect to accreditation mechanisms, to the best of the research team's knowledge, thus far, no agency supporting more than 200 individuals in one setting has received accreditation under the outcome standards.

### *The Regulatory Basis for the Outcome Focus*

Where the state has an explicit vision and mission statement in legislation, the outcomes focus has a firmer basis; this is true for Oklahoma, Massachusetts and Colorado, and somewhat less so for Utah. Many more of the study states have some or all of the outcome-oriented QA mechanisms stipulated in consent decrees, which has in some cases been a springboard for using the tools more broadly than simply for class members (especially in Oklahoma).

### *Integration Among QA Mechanisms*

Findings from outcome-oriented surveys have not been widely shared in the study states, nor have the data been routinely analyzed in conjunction with other quality assurance data sets. In terms of information-sharing, the consumer survey findings are shared less than are the citizen monitoring or certification survey results. Both Colorado's COPAR and Oklahoma's consumer assessment have not been routinely shared with case managers or providers. In Oregon, by contrast, the ROS findings are promptly fed back to direct care staff, to help them reflect on their own practice. None of the states gives the consumer interview information to licensing or certification authorities, although such information in the aggregate could offer valuable insight into provider performance. Citizen monitoring reports are commonly shared with other QA authorities as well as with providers. WY does better than other states in sharing information, probably because it is a smaller system.

Analysis of the outcomes data has similarly been fairly limited. Colorado has done extensive analysis of the COPAR results, both longitudinal and cross-sectional, but with no formal linkage between COPAR and other data sets. Oklahoma has followed a similar pattern with its longitudinal consumer assessment data. Oregon has begun to do some longitudinal analysis of the ROS data, but nothing has been done with AIM results. Wyoming is beginning to consider a more extensive analytic QA function through the UAP. Utah has done limited analysis of the QE outcome surveys, comparing performance across residential settings and ICAP levels.

Many of the states make use of the outcome-focused QA information for policy purposes. Colorado sees COPAR's primary function as influencing state policy, and New York's COMPASS has a comparable program evaluation focus. Several of the study states share results of the consumer surveys with legislature

and/or governor -- for example, annual reports from the DD offices in Utah, Colorado, and Oklahoma. Several states distribute QA information very broadly -- Utah's DSPD has a *Consumer Report on Home and Community based Services*, to provide information to consumers to assist them in choosing service providers; it indicates how each agency performed on the QE survey, the consumer satisfaction surveys, and the volunteer monitoring visits. Oklahoma attempted to do a consumer report but found such resistance from providers that they abandoned it. Wyoming DDD publishes and widely disseminates the reports of their CARF-based state certification visits.

Several states are attempting to improve the integration of QA information from various sources, so that it becomes more useful for both policy and practice. The preferred vehicle for these efforts is collaborative planning groups:

- Oregon's QA Summit group, composed of representatives of all parties engaged in some QA activity, is meeting quarterly to develop joint ownership in quality assurance, to collectively develop strategies for fixing things, and to build a process to integrate/link data from the various QA mechanisms; the goal is to identify some key questions, benchmarks of quality, and, in the process, stimulate similar efforts at the county level to link QA information and assess their own performance.
- Utah's Futures Directions Strategic Planning group, composed of representatives of all key stakeholders, meets annually to guide DSPD in its services and QA system. The group reviews the prior year's action plans, recommends changes, publishes a report, and celebrates accomplishments.

### *Stakeholder Involvement*

Citizen involvement is the core of the volunteer monitoring processes. All of the study states have some type of advisory body to the DD office, and most have advisory bodies/steering committees for specific QA components (e.g. COMPASS, COPAR). Colorado's agency-directed surveys can include non-professionals as team members, and Missouri's certification survey teams include consumers, families, and providers.

### **Themes and Recommendations**

Based on the 50 state survey and the state site visits, there are some general themes that are important to HCFA's considerations regarding future regulatory directions.



### *Relevance of Outcome Measures to Large ICFs/MR*

With some exceptions, the outcome-based mechanisms that were reviewed were not uniformly applied to people who live in large ICFs/MR. Where they were applied, as in Massachusetts, the facility did not score favorably compared to community-based residences, although the process was seen as positive for those who worked in such facilities. The absence of these facilities from the state initiatives also means that there is not much information gained from the state site visits regarding the use of the measures on people living in large institutions. The analysis conducted by Temple University (summarized in the following section) as part of this project, however, does show that the instruments do have applicability in these settings.

It is therefore recommended that any change in HCFA's current regulations regarding the selected outcomes be applied across ICF/MR settings regardless of size. The current absence of such oversight mechanisms in large public institutions should not justify the development of a bifurcated system in which people who live in institutions are not subject to the achievement of the selected outcomes.

### *Increase in the Use of Self-Assessments*

In many of the states, reliance on self-assessments was increasing. In some states, like New York and Colorado, providers chosen to carry out self-assessments were those with high scores on traditional quality assurance reviews. By doing a self-assessment, providers were excused from these regular regulatory reviews. In New York, follow-up evaluation showed that where agencies did self-assessments, they still maintained compliance with formal requirements -- in some instances at higher levels than previously. The motivation for the increased use of self-evaluation was both born of necessity (shrinking resources at the central level), as well as a commitment to quality enhancement. Advocates interviewed in Colorado expressed deep concerns about this trend. However, providers interviewed in New York and Colorado saw the self-assessment as a positive step and a sign of increased public/private collaboration between the agency and the state.

Given the current and potential limitations on state quality assurance resources, the use of self-assessment in conjunction with some aspects of formal monitoring for those providers who have demonstrated a commitment to quality, can both stretch QA resources and reward outstanding providers. However, it is recommended that some threshold health and safety review be maintained.

### *Interviewing People with Severe Disabilities/Limited Communication*

Virtually all of the outcome systems that were reviewed involved some level of consumer response regarding outcomes they are experiencing and, in most cases, their satisfaction with services and supports. All of the outcome measurement systems involved direct contact with consumers and many states and localities employed additional consumer satisfaction measures. While this emergence of consumer-centered quality assurance is admirable, some questions did emerge regarding the use of interviews on outcomes for people with significant communication limitations, such as their choice-making, opportunities for inclusion and relationships, and satisfaction. Some questions were also raised about the numbers of individuals that could respond to quality assurance and outcome surveys. In Colorado, the estimates were about 25% and key informants in other states noted similar limitations. In some states, such as New York proxy respondents (family and direct support staff) were used to complete the information. There is some concern, however, that such partial data may be used to justify program performance in the absence of other reviews or more innovative approaches to obtaining consumers' perspectives on outcomes.

This finding has several implications. First, as noted in Report #2 regarding the current ICF/MR review process, surveyors will need systematic training to communicate with people with severe and profound disabilities and to elicit information from those who are closest to the individual. Secondly, consumer "satisfaction" cannot be the only measurement of quality -- consumer survey approaches must be coupled with ongoing health and safety, some program or "process" reviews, and the use of objective performance indicators (see the report with respect to Task B of this project).

### *Training Surveyors in Outcome-Based Methods*

Most state quality assurance officials emphasized the importance of training surveyors in using new outcome-based instruments and related techniques, in particular interviews and observations. In Colorado, the state program agency trains surveyors hired by a private contractor, while the New York program office trained a subgroup of surveyors in the COMPASS program. Surveyors also received special training in Massachusetts on QUEST. Training was considered important in shifting to outcome-focused quality assurance to re-orient surveyors used to traditional licensure reviews, to enhance skills in obtaining information through interviews and observation, and to improve inter-rater reliability. It also has been suggested that many ICF/MR surveyors will need considerable (re-) training in order to shift to more of an outcome focus.

With respect to HCFA's concerns, this finding underscores the importance of the current surveyor training initiative as well as the maintenance of a training program directed at outcomes in the future.



### *Outcome Measurement and Direct Support Staff*

Outcome, consumer-focused approaches were very popular with direct support staff who saw them as a validation of the importance of their work and the people that they serve. Interestingly, they were more positive in most instances than the administrators of programs.

This finding strongly suggests that any outcome-focused quality assurance mechanism should include organizational development strategies that assist direct support and other staff to understand the implications of an outcome focus for their agency in contrast to more process-oriented approaches. Training would include the importance of respecting the preferences and goals of people with mental retardation, the ways in which staff performance reviews would be tied to reconfigured expectations based on outcomes, and the ways in which outcomes would be reported and represented.

### *Importance of Organizational Development*

Many of the quality assurance systems reviewed included either an implicit or an explicit emphasis on the organizational development of providers. Given the significant changes that many organizations must initiate in order to manage services in a more "outcome oriented" fashion, the inclusion of an organizational development strategy would appear to be an important ingredient. The most explicit example of an organizational development approach combined with an outcome focus was the COMPASS program in New York. To become a COMPASS agency, programs were required to develop strategic plans, internal QA systems, and a consumer-focused approach.

This finding suggests that HCFA should consider revising the Conditions of Participation in the ICF/MR program to include an explicit requirement for organizational development aimed at a transition to an outcome focus.

### *Role of Citizen Monitoring*

Citizen monitoring of programs for people with mental retardation was a facet of many of the quality assurance systems reviewed. Citizen monitoring has the benefit of extending scarce monitoring resources and providing multiple perspectives including families and people with disabilities. Citizen monitoring, however, requires significant coordination and support to ensure the integrity of the process. In some of the states reviewed, the strength of citizen monitoring had waxed and waned over the years and while it is clearly an important element of a quality assurance system, it has been difficult to elevate it to a more central role than it currently occupies.

It is recommended that HCFA consider, as a condition of participation in the ICF/MR program, the presence of an external monitoring entity -- preferably that includes citizens and people with disabilities.

### *Health and Safety Protections*

The conversion of ICFs/MR and the reduction in the size of residential arrangements has meant that ICF/MR regulations and state licensing requirements aimed at larger settings (e.g., 5 or more beds) are not relevant to many small residential arrangements. In Colorado, for instance, licensing does not apply to residences under four beds. Further, without ICF/MR regulations, there may not be any requirements that incidence and abuse reports get communicated to central authorities. While the decline of potentially unnecessary regulation is positive, there were informants who expressed some anxiety about the loss of some basic protections. Throughout most of the states visited, there were efforts to "streamline" regulations and to reduce their complexity. However, it should also be noted that in the states visited, health and safety issues were either included in the outcome monitoring mechanism, or were part of parallel licensing and certification procedures.

To the extent that this is a federal issue, it affects the way in which the federal waiver program is implemented since community residences are increasingly supported by waiver funding. It is suggested that joint discussions be held between federal waiver and ICF/MR officials to discuss a joint strategy to ensure that valuable protections are not diminished.

### *Importance of Stakeholder Consensus*

An important ingredient in the implementation of the outcome structures reviewed for this project was the emphasis placed on the development of consensus among all key stakeholders including people with disabilities, families, providers and policy makers. In Missouri, for instance, the development of that state's new outcome-based certification process involved a wide range of stakeholders from around the state. In New York, the state QA officials worked with a consumer board to implement the COMPASS approach. In other states, stakeholder groups have been convened to review the information gained from the outcome monitoring process.

It is recommended that HCFA signal its concern from broad based participation in quality assurance plans in any future regulations.

### *Growing Use of Accreditation*

Some states are using accreditation as the core or an alternative to their quality assurance process. Many other states, as they contemplate managed care, are also considering accreditation as a means of certifying eligible agencies. Both accreditation schemes, ACD and CARF, have moved to an outcome focus. The potential expansion of the "privatization" of quality assurance should be an important consideration in any future HCFA plans for ICFs/MR.

Given the potential expansion of accreditation as a means of ensuring program quality, HCFA should consider the possibility of allowing ICFs/MR to substitute accreditation compliance with the explicitly programmatic aspects of federal standards.





### **Objective 3: Review of the reliability and validity of selected quality assurance instruments**

#### **Summary of Findings**

##### ***Face Validity***

Data collection efforts in the seven states and the two accreditation agencies yielded some very promising results. In addition to having the attribute of face validity, which was evident in the development of the instruments used to assess outcomes, many of the instruments proved to be reliable and valid.

##### ***Reliability***

The reliability of the instruments assessed overall was favorable. In five of the nine states and organizations reliability was found to be well within acceptable ranges. The states included: Colorado, Massachusetts, Missouri, Oklahoma, and Oregon. In Utah, where a reliability study was conducted, the reliability rate was unacceptable. This was thought to be related to the lack of experience of one individual. Utah plans to redo its reliability study once this individual has had additional training. With regard to New York, the instrument was found to be unreliable. Interestingly, it has been determined that the instrument will no longer be used. In terms of the accrediting agencies, the Accreditation Council is currently in the process of completing an extensive reliability study. It would be our recommendation that CARF undergo similar efforts.

##### ***Concurrent Validity***

In terms of concurrent validity, the results were not as promising. Concurrent validity was found to be acceptable for three of the nine states and agencies (CO, OK, OR) marginal for 5 of the states and agencies (MA, MO, UT, AC, CARF) and unacceptable in one state (NY). After careful analysis of the data, it became clear that there were several possible explanations for the weakness of these findings. First, in many cases where concurrent data using the Temple BDS were collected long after the State and Agency data had been collected, it is possible that things had really changed. In the case of AC, for example, the Temple BDS data were collected about one year after the Accreditation Survey had been completed. There is no doubt that within one year, things had changed. Second, in many cases the reports that were used to produce the concurrent data from the states and agencies were site data rather than individual data. In that situation, the score of the agency was attributed to each individual and then compared to data that were collected at the individual. It is for this reason, we believe, that the states where the concurrent validity analyses produced the strongest results were the

states where individual data are collected. Future efforts should be targeted toward obtaining enough site data to truly look at a large number of agencies and sites.

### *Applicability*

Applicability was acceptable in five of the nine states and agencies (CO, MA, NY, OK, CARF), marginal in one agency (AC), and unacceptable in three states (MO, OR, UT). The lack of applicability in the three states is not related to inability to be applied in larger settings, but rather because those three states have chosen to use the outcome assessments only in the community programs. In terms of AC, no facility has been accredited that is larger than 120 individuals.

In terms of discriminant validity, acceptable relationships were found in five of the nine states and agencies (CO, MO, NY, OK, UT), and in the remaining states and agencies there were insufficient data to complete the analyses. In terms of the two accrediting agencies and the State of Massachusetts, because scores are ascribed to agencies, the discriminating variables have nothing to predict. In other words, if one wanted to assess the ability of level of mental retardation (4 levels) to predict integration and there is only one integration score for everyone in the facility the lack of variance makes such an exercise futile. On the other hand, the State of Oregon maintains no demographic data on the outcome data system; therefore there were no predicting variables available for analysis.

Health and Safety data were collected in all nine states and agencies. In most states and agencies, the Health and Safety data were compared with the states' outcome data. In all states, comparisons were made with state licensing data and ICFs/MR OSCAR data. Comparisons between the outcome data and the Health and Safety data yielded only a few significant correlations, most of which appear to be spurious. This may be due to the fact that no significant relationship between outcomes and health and safety was measured. As a result, it is the study team's firm belief that the two dimensions be assessed separately. There were correlations between the state and federal deficiency data and some of the health and safety scales. Overall, our conclusion is that the Health and Safety scales were not highly correlated with any of the outcome measures analyzed.

The results of the various analyses are summarized in Table 1-11 below.



**Table 1-11**

**SUMMARY OF PSYCHOMETRIC PROPERTIES OF INSTRUMENTS  
AND HEALTH AND SAFETY ANALYSES**

	Reliability	Concurrent Validity	Applicability	Discriminant Validity	Health & Safety
CO	Assessed by Temple, acceptable	Assessed by Temple, acceptable	Assessed by Temple, acceptable	Assessed by Temple, acceptable	Assessed by Temple
MA	Assessed by MA, acceptable	Assessed by Temple, marginal	Assessed by MA, acceptable	Assessed by Temple, insufficient data	Assessed by Temple
MO	Assessed by MO, acceptable	Assessed by Temple, marginal	Unacceptable	Assessed by Temple, acceptable	Assessed by Temple
NY	Assessed by Temple, unacceptable	Assessed by Temple, unacceptable	Assessed by Temple, acceptable	Assessed by Temple, acceptable	Assessed by Temple
OK	Assessed by OK, acceptable	Same scales, acceptable	Assessed by OK, acceptable	Assessed by Temple, acceptable	Assessed by Temple
OR	Assessed by OR, acceptable	Assessed by OR, acceptable	Unacceptable	Assessed by Temple, insufficient data	Assessed by Temple
UT	Assessed by UT, unacceptable	Assessed by UT, marginal	Unacceptable	Assessed by Temple, acceptable	Assessed by Temple
AC	Currently being assessed by AC	Assessed by Temple, marginal	Assessed by AC, marginal	Assessed by Temple, Temple insufficient data	Assessed by
CARF	Insufficient data	Assessed by Temple, marginal	Assessed by Temple, acceptable	Assessed by Temple, Temple insufficient data	Assessed by

## Implications and Recommendations

In summary, the quantitative portion of this study demonstrated that there are systems currently in use in the states that in addition to having been developed over long periods of time with significant thought and input from various stakeholders, many of the systems possess strong statistical properties. The study team offers the following recommendations regarding the implementation of outcome-based quality assurance systems:

- 1) All systems should be tested for reliability, validity and applicability across settings and across individuals with a variety of disabilities;
- 2) In systems where scores are ascribed to facilities rather than individuals, great pains should be taken to insure that the facility scores adequately represent the experience of the individuals supported; in other words, greater attention needs to be paid to the issue of appropriate sample size;
- 3) Health and safety should be assessed separately from the assessment of outcomes;
- 4) Stakeholders must decide whether the outcome systems are assessment systems, technical assistance systems or a combination of the two - this should be clearly articulated from the outset

#### **Objective 4: Results of the review of empirical studies of outcome focused quality assurance**

##### **Summary**

While some commonalties exist among states moving to incorporate quality of life outcomes into their evaluation strategies, it is clear that each state is forging its own path. This may, in part, be attributed to the plethora of "quality of life" definitions and measurement approaches. In one recent study (Hughes, Hwang, Kim, Eisenman & Killian, 1995) reviewing literature from the past two decades, 44 distinctly different definitions of quality of life were discovered. While the fundamental "dimensions" or "components" of quality of life parallel those utilized in this project study, it is important to note that they encountered over 1200 unique measures used to assess these dimensions.

The areas of independence, social relationships, community integration, self-determination/choice, and consumer satisfaction were common elements for assessment in most of the studies identified. Another consistency included state efforts to make comparisons between results for varying service options (more specifically residential options), and comparisons based on the extent of disability experienced by service recipients.

The differences, however, far outweigh the similarities. The specific indicators or target areas of quality vary in nature. Comparisons between residential settings are inconsistent across states (e.g., institution vs. community, ICF/MR vs. HCBW funded settings, small vs. large community settings). And although use of surveys and interview protocols are generally accepted practice, measurement tools and approaches vary significantly.

In summary, very little data and reporting exist related to empirical studies of quality outcomes, and among that which does exist, there is minimal consistency across studies. While it is evident that states are moving toward outcome-driven quality assurance systems, there remains considerable need to develop consensus over the factors defining quality of life, the appropriate measurement options, tracking and reporting of assessment results, and the utilization of results and analyses in directing policy decisions for services and supports designed to assist people with developmental disabilities.





## IV. BRIEF SUMMARY OF FINDINGS AND RECOMMENDATIONS

### Summary

The results of this project strongly indicate that many states have established or are in the process of developing outcome-focused quality assurance mechanisms that encompass the selected outcomes as well as other important benefits. While not all states have developed systematic outcome monitoring approaches, the 7 states visited by project staff are committed to outcome monitoring and are variously in the process of imbedding such schemes in their ongoing quality assurance/quality enhancement systems. On the basis of key informant interviews in the states, it also appears that the move to outcomes was accompanied by the maintenance of health and safety protections albeit in a somewhat different form.

Further, the analysis of the psychometric properties of the instruments used in each of these states shows that the majority are reliable, applicable to institutional populations and discriminate among categories of consumers in an acceptable fashion. Concurrent validity was found in three of the most established state QA instruments -- Colorado, Oregon, and Oklahoma, but was inconclusive or inadequate in the remaining states. Finally, no significant correlations could be found between outcome scores and health and safety indicators.

Several variables were important in the success of the systems reviewed in the study states including a commitment from state leadership, broad stakeholder participation, the provision of assistance to enhance the acceptance of outcome monitoring, participation of family members and people with disabilities, commitment of direct support staff, and development of a continuous quality improvement philosophy. Other factors also appeared to play an important role as catalysts for the creation of outcome approaches including the presence of a major lawsuit and the infusion of new service dollars into the system.

With respect to the identification of quality indicators, project staff listed a range of areas that could be used by HCFA as a basis for developing quality indicators to both monitor the well-being of people living in ICFs/MR as well as their progress on valued outcomes.

In addition to recommendations included in each project report, presented below are our suggestions for concepts that HCFA could consider as they build the future quality assurance system for this program.

## *Performance Contract*

HCFA should consider further investigation into the value of entering into performance contracts with each state that supports people in ICFs/MR. Any such approach should include the following:

- Evidence that the contract represents a collaboration between the Mental Retardation/Developmental Disabilities, the state certification agency, and the state Medicaid agency.
- A plan that includes a process for: 1) ensuring that ICF/MR providers implement a continuous quality improvement system, 2) a mechanism for collecting data on valued outcomes, 3) an external monitoring process that includes citizens and consumers, and 4) a process for building organizational capacity regarding the implementation of an outcome-focused approach to the provision of care and supports, including the retraining of staff, changes in staff performance reviews, and proposals for monitoring outcomes within an agency.
- A proposal to monitor the health and safety of residents of ICFs/MR including the development of individual health and safety plans where appropriate. Such an agreement should also include an affirmation to submit data on selected health and safety indicators developed by HCFA.
- A mechanism to ensure that residents of ICFs/MR receive active treatment (e.g., traditional surveys, accreditation, or other certification process).
- An agreement to prepare yearly reports regarding that status of performance contract activities and the steps taken to enhance care and supports in ICFs/MR. This report should also include information on ways in which the results of state quality assurance efforts are made available to consumers of service as well as to family members and other interested parties.

## *Performance Indicators*

We suggest that HCFA develop a set of quality of life and health and safety indicators based on the methodology described in the report submitted pursuant to Task B of this project. The development of such a data set would require an exploration of those individual indicators currently extant that are most likely to predict conditions that may jeopardize either the health and safety or the quality of life of ICF/MR residents. These indicators in turn should be used as "red flags" to trigger more in-depth review by HCFA regional surveyors. These in-depth "red flag" reviews should be conducted using current federal health and safety standards. We further suggest that HCFA take



the lead in developing and publishing national norms for these indicators, through periodic national surveys.

### *Active Treatment*

Our opinion in reviewing the HCFA ICF/MR regulations is that the current regulations, while providing significant assurances that residents of ICFs/MR receive a wide range of needed interventions, rely too heavily on professional perspectives and are perceived as too prescriptive.

Although the most recent proposed changes in the active treatment regulations (March 18, 1996 memo) move in a positive direction, there are still areas that can be improved including a de-emphasis on the assessment of needs in favor of an increased emphasis on eliciting goals and preferences, a more explicit bridge between the notions of active treatment and the new supports orientation of the AAMR Definition, and a more prominent role for person-centered planning. Further, it is suggested that HCFA consider becoming a center for excellence in quality assurance with responsibility to distribute state-of-the art information on innovative quality processes and dissemination of analyses of quality trends based on the collection of performance indicator data.

We suggest that HCFA continue to refine the definition of active treatment based on the recommendations included in Report #2. We further suggest that surveyor training curricula be supplemented to include an introduction to the supports model, an orientation to the new definition, a discussion of person-centered planning, and an examination of the ways in which to elicit responses from people with severe disabilities.

### *Applicability to All HCFA Funded Services to People with Mental Retardation*

Several factors suggest that some of the recommendations listed should pertain to persons with mental retardation regardless of where they live, including the fact that: 1) many states are rapidly downsizing and phasing out many public and private ICF/MR beds; 2) managed care organizations will play a larger role in the allocation of Title XIX funds in long-term care; 3) provider networks may replace traditional sub-state administrative structures; and 4) many people who previously resided in ICFs/MR are now living in waiver funded programs.

For these reasons, we would strongly suggest that at least those portions of the recommendations discussed above that deal with quality of life indicators, continuous quality improvement, external monitoring, and the publication of quality assurance

findings be included in requirements for the Home and Community Based Waiver Programs (1950(b)) as well as included in the criteria for the approval of 1115 managed care waivers.

**Report #2**  
**Analysis of the Application of the Active Treatment Definition**  
**(Objective 5, Task A)**

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**REVIEW OF THE CURRENT DEFINITION OF ACTIVE**  
**TREATMENT AND RELATED ICF/MR QUALITY**  
**ASSURANCE ACTIVITIES**





**REPORT #2**  
**ANALYSIS OF THE APPLICATION OF THE ACTIVE TREATMENT**  
**DEFINITION**  
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Appendix B	1	Behavioral Development Survey
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	2	Comments on Revised Conditions of Participation for ICFs/MR
Appendix E		Cumulative List of all Interviewees
Appendix F		Combined References (Tasks A & B)



## **Report #2**

### **Analysis of the Application of the Active Treatment Definition (Objective 5, Task A)**

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## **REVIEW OF THE CURRENT DEFINITION OF ACTIVE TREATMENT AND RELATED ICF/MR QUALITY ASSURANCE ACTIVITIES**

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### **BACKGROUND**

The Health Care Financing Administration (HCFA) has asked the Human Services Research Institute (HSRI) to make determinations about those aspects of HCFA's regulatory definition of active treatment, including HCFA's interpretative guidelines, that are consistent with contemporary notions of support and those that hamper such concepts. Because of the linkage of the active treatment definition and guidelines with other aspects of ICF/MR quality assurance (e.g., the pilots of new survey approaches conducted spring 1995 and the Independent Professional Review/Utilization Review component of ICF/MR quality assurance), HSRI's review encompassed these and other related elements. Although HCFA requested that we provide, to the maximum extent possible, empirical data to support or refute our determinations (i.e., data from studies which employed statistically valid sample sizes and methods), no such data were identified.

The definition of active treatment is central to the ICF/MR quality assurance program in at least four ways:



1. *Condition of Participation in the ICF/MR program:* Facilities must meet the active treatment Condition of Participation (CoP) at §483.440 in order to be certified as ICFs/MR.
2. *Principal focus of the ICF/MR survey:* Assessment of the delivery of active treatment services is identified in *Appendix J: Survey Procedures and Interpretive Guidelines for Intermediate Care Facilities for the Mentally Retarded* (HCFA, 1988; 1996) as the primary focus of the survey.
3. *Determination of eligible beneficiaries:* Only individuals with mental retardation or related conditions who are in need of continuous active treatment are eligible for ICF/MR services. ICFs/MR are required to meet the standard that "Clients who are admitted by the facility must be in need of and receiving active treatment services" (§483.440(b)(1)).
4. *Reimbursement allowances:* Facilities may receive reimbursement only for the cost of care of individuals classified for the ICF/MR level of care who are receiving active treatment.

The active treatment CoP section of *Appendix J* begins with the active treatment standard at W195, followed by five standards and 70 areas of review (tag numbers):

- W196-197: Active treatment definition;
- W198-205: Admissions, transfers and discharge;
- W206-248: Individual program plan, including IPP development by the interdisciplinary team, the comprehensive functional assessment;
- W249-251: Program implementation; and
- W252-265: Program documentation, including program monitoring and change as well as requirements for a specially constituted committee and informed consent for behavioral training programs that involve risks to client protection and rights.

Revisions to *Appendix J, Interpretive Guidelines for ICFs/MR* effective December 4, 1995, include Condition Level Compliance Principles for W195 and Facility Practice Statements on 50 of the 70 active treatment tag numbers. In addition, the new Fundamental Survey described in the revised *Appendix J* to be effective July 1, 1996, and implemented no later than October 1, 1996, calls for initial review of a core group of 15

tag numbers in determining the Active Treatment CoP, with remaining requirements considered as supporting structures or processes that the facility must implement. The revised *Appendix J* also increases the survey's focus on outcomes and on observations and interviews as the primary methods of information gathering. Surveyor training taking place in the Spring and Summer 1996 incorporates these concepts and approaches.

HSRI's review of the active treatment definition and related ICF/MR quality assurance activities has spanned the period of time when revisions in *Appendix J* were being made. Most of the information on active treatment quality assurance analyzed by HSRI was related to standards and surveys based on the 1988 edition of *Appendix J*. Where appropriate, however, we have included actual and proposed revisions to *Appendix J* in our review, as well as the informal draft proposal for revised ICF/MR regulations (HCFA, March 1996). It is clear from many of the actions taken by HCFA since we began our review in late 1994 that HCFA is moving to bring active treatment quality assurance more in line with contemporary notions of state of the art service delivery and with effective outcome-based quality assurance principles that are compatible with the support model.

## METHODOLOGY

HSRI used six sources of information in conducting the review:

1. Informal discussions with State contacts across the nation regarding their experience with ICF/MR quality assurance and perspectives on the active treatment regulations and guidelines, in conjunction with the development of the Task A Interim Report. A total of 60 informants in 41 States with experience with ICF/MR surveys provided information on active treatment and related ICF/MR quality assurance, and on suggested reforms (names and titles of these individuals are provided in Appendix A):
  - Thirty-five quality assurance staff in State mental retardation/developmental disabilities agencies, including 23 State quality assurance directors, 6 quality assurance staff for community residential services or other State quality assurance responsibilities, and 6 individuals with responsibility for quality assurance in one or more State facilities;
  - Seven directors of State mental retardation/developmental disabilities service agencies;



- Sixteen State mental retardation/developmental disabilities staff with responsibilities such as community services, policy development, and regional service administration;
  - One administrator of Medicaid services for people with mental retardation/developmental disabilities; and
  - One provider.
2. Interviews with knowledgeable individuals during site visits to eight States conducted to review outcome-focused quality assurance systems (additional Task A activities reported on in a separate document), including State mental retardation/developmental disabilities agency staff, ICF/MR surveyors, QMRPs, administrators of State institutions certified as ICFs/MR, and providers of community ICF/MR services. Names and titles of these individuals are provided in Appendix E (indicated by an \*).
  3. Literature on ICF/MR quality assurance:
    - Formal literature (e.g., peer reviewed journals), including ICF/MR program history and perspectives on ICF/MR quality assurance; and
    - Informal literature (e.g., conference presentations).

As noted above, the literature search did not identify any empirical studies on consistency between ICF/MR active treatment quality assurance and contemporary notions of support.
  4. Input from members of the Technical Working Group and their respective organizations, as appropriate. In this context, project staff participated in discussions of the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, the American Network of Community Residential Options, and the ICF/MR Task Force of the American Health Care Association regarding ICF/MR quality assurance.
  5. Telephone interviews with additional knowledgeable informants in seven study States, targeted specifically to members of ICF/MR survey teams, administrators in State facilities certified as ICFs/MR, and five additional community ICF/MR providers in another four states. As approved by the HCFA project officer, these interviews were conducted to obtain additional information on active treatment quality assurance in lieu of HSRI's direct observation of an ICF/MR survey. Names and titles of these individuals are provided in Appendix E.(indicated by an \*).



6. HCFA documents on ICF/MR quality assurance, including:

- *State Operations Manual: Provider Certification. Transmittal No. 212 (October 1988).*
- *Draft No. 6 Revised Survey Procedures, July 1995.*
- *Revised Exhibit 80 and Appendix J (J-13 - J-138), December 1995.*
- *ICF/MR Conditions of Participation (Proposed 1996 Draft), March 18, 1996.*
- *Draft Revised Exhibit 80, Sections 2900-2901 and Appendix J (J-1 - J-20), spring 1996 (to be effective July 1, 1996).*

Comments on the *Draft No. 6 Revised Survey Procedures* and on the informal draft of proposed ICF/MR Conditions of Participation previously submitted are included in Appendix D of this report.

HSRI's review and analysis was affected by three factors: the changes in ICF/MR quality assurance being undertaken by HCFA, as discussed above; the need to broaden the scope of our analysis beyond the definition of active treatment and the guidance to surveying the active treatment CoP; and the difficulty in determining what is due solely to Federal regulations and requirements for the review of active treatment.

Because a major part of our charge was to look at active treatment in relation to contemporary notions of quality, HSRI used consistency with the primary outcomes defined by the Technical Working Group as one basis for its analysis. The primary outcomes are as follows:

- |                                    |                         |
|------------------------------------|-------------------------|
| • Self-determination               | • Personal growth       |
| • Dignity                          | • Individualism         |
| • Community integration/inclusion  | • Health and safety     |
| • Relationships/social connections | • Consumer satisfaction |

Both "self-determination" and "individualism" were associated with the concept of consumer choice, an identified area of interest to HCFA in our review of active treatment. Perspectives of active treatment out in the field, however, often encompass standards and survey issues that are not within the active treatment CoP, such as limitations on choice-making in the dietetic services section of the standards, discussed

below. In addition, some of the guidance that is particularly strong in its consistency with choice and the primary outcomes is found in the draft revised *Appendix J* Compliance Principles and Facility Practice statements for the Client Protections CoP and the Client Behavior and Facility Practices CoP.

In order to relate the monitoring process to active treatment issues, it was necessary to review the survey methodology itself, and the extent to which the review of active treatment during the survey process (or, in some cases, the anticipation of a survey from previous experience) affects the provision of state-of-the-art services. Specifically survey procedures were reviewed in light of the common linkage between state-of-the-art services, in particular person centered planning and the support model, and the shift to outcome-focused quality assurance methodologies. This linkage was apparent throughout the States that had moved to more outcome-based quality assurance, as described in the *Interim Task A Report*.

Regarding perspectives on the consistency of Federal standards with contemporary concepts, HSRI found throughout its analysis that it is virtually impossible to isolate the effects of the Federal regulations and survey procedures required by HCFA in isolation from state requirements. In some cases, State and local regulations that go beyond Federal standards are a source of problems with active treatment quality assurance. In a California facility, for example, the QMRP reported that the State ICF/MR survey team cited the program because a client's Nintendo game was stored in the living area with the facility's entertainment center and did not have the client's name on it nor was it stored in the client's room. According to the QMRP, the client wanted the game to be available to his roommates, which was explained to the surveyors. The citation, however, was for W109--compliance with Federal, State and local laws on sanitation--rather than a Federal standard requiring labeling or storage in an individual's room. The perception, however, was that it was ICF/MR rules that were interfering with a normalizing activity.

Similarly, it is often difficult to identify misapplications of Federal standards by individual survey teams, or to separate perspectives on actual regulations from those stemming from misapplications. There are still reports, for example, of surveyors requiring specific numbers of objectives in Individual Program Plans (IPPs) or of a predetermined number of hours of day services, leisure activities, etc., in order to comply with active treatment standards. Although HCFA continues to try to clarify that these kinds of requirements are not part of the Federal regulations, through its guidelines in *Appendix J* and surveyor training programs, providers continue to report that some surveyors impose them. This perpetuates the perception that it is ICF/MR standards that require "over-programming" or excessive paperwork. Facilities that

have experienced such surveys also may continue to respond to such misapplications, in fear of being cited again. The effects of misapplications may therefore persist, despite HCFA's best efforts to counteract them.

In addition to the primary outcomes, our review of perspectives on the active treatment definition and its use in ICF/MR surveys focused on concepts of the support model. The evolution that has taken place to the individual support model is summarized in the following:



The first of these is the fact that the  
government has been unable to  
maintain a stable currency.

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government has been unable to  
maintain a stable currency.

The third is the fact that the  
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government has been unable to  
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The ninth is the fact that the  
government has been unable to  
maintain a stable currency.

**TABLE 1**

**FOCAL QUESTIONS FOR THREE HISTORICAL ERAS**

Focal Questions	Era of Institutions	Era of Deinstitutionalization	Era of Community Membership
Who is the person of concern?	The patient	The client	The citizen
What is the typical setting?	An institution	A group home, workshop, special school, or classroom	A person's home, local business, the neighborhood school
How are the services organized?	In facilities	In a continuum of options	Through a unique array of supports tailored to the individual
What is the model?	Custodial/medical	Developmental/behavioral	Individual support
What are the services?	Care	Programs	Supports
How are services planned?	Through a plan of care	Through an individualized habilitation plan	Through a personal futures plan
Who controls the planning decision?	A professional (usually an MD)	An interdisciplinary team	The individual
What is the planning context?	Standards of professional practice	Team consensus	A circle of support
What has the highest priority?	Basic needs	Skill development, behavior management	Self-determination and relationships
What is the objective?	Control or cure	To change behavior	To change the environment and attitudes

Adapted from "The New Service Paradigm" (Bradley, 1994).





## RESULTS

A cross-section of individuals (i.e., State program agency officials, surveyors and ICF/MR managers) indicated that the support model can be done within the active treatment regulations, but only if two factors are present:

1. the ICF/MR is firmly committed to a focus on outcomes and quality of life, and
2. the ICF/MR surveyors understand the value of the support model and can integrate the concept into an active treatment framework.

At the present time, however, these conditions appear to be the exception across the country. Despite the general trend toward the support model and a strong focus on consumer centered outcomes and quality of life, there is considerable variation among ICF/MR providers in the degree to which this is a reality. Similarly, there are many differences among surveyors in their understanding of contemporary approaches and in their commitment and comfort level with an outcome-based survey. Regulations may therefore be applied inconsistently across the States. Although surveyor training, coupled with HCFA oversight and technical assistance, can help, it is likely that differences among surveyors will persist to some degree. In States with very few ICFs/MR, for example, or those with no small community-based ICFs/MR, surveyors may have minimal exposure post-training to state of the art services, especially if the majority of their survey work is done in nursing facilities. For this reason, it will be necessary for HCFA to adopt a more active posture in assisting surveyors to make the connection between the rhetoric of the ICF/MR standards and the concrete application of the support model.

## Perspectives on Active Treatment

The term "active treatment" has been central to the ICF/MR benefit since its initial authorization in Public Law 92-223 in 1972. P.L. 92-223 reflected Congressional recognition that the needs of individuals with mental retardation often differ significantly from elderly long term care beneficiaries with disabilities, by authorizing FFP for "rehabilitative service" as well as for health care. This was the first time that Medicaid FFP was authorized for institutional care that was not primarily medically oriented or only "health related" (Boggs, Lakin & Clauser, 1985). These principles are addressed in the regulatory definition of active treatment, which is as follows:

Each client must receive a continuous active treatment program, which includes aggressive, consistent implementation of a program of generic training, treatment, health services and related services described in this subpart, that is directed toward (i) the acquisition of the behaviors necessary for the client to function with as much self determination and independence as possible; and (ii) the prevention or deceleration of regression or loss of current optimal functional status (42 CFR 483.440).

HSRI found that some State program agency staff continue to see active treatment as a strength of the ICF/MR program, as opposed to custodial care and lack of opportunity for ICF/MR residents with severe disabilities. These officials see active treatment requirements as a way to prevent a return to custodial care because of the assumption that everyone can benefit from interventions--i.e., that individuals with very severe disabilities are not "developmentally incapable." Additional strengths in current ICF/MR quality assurance noted by some State program agency informants include:

- Help from Federal on-site training, and the mentoring role played by Federal surveyors;
- The importance of the team approach.
- Improvements in the process as a result of an increased emphasis on observations and interviews.
- The need for the essential minimum protections embodied in Federal standards.

With respect to constraints, the majority of State program agency staff and ICF/MR managers identified one or more of the following concerns:

- Compliance does not equate with quality;
- The standards are not focused on outcomes;
- The processes that are reviewed are not sufficiently linked to desired outcomes;
- The yes/no dichotomy (i.e., in or out of compliance) ignores individual differences;
- The adversarial approach of the survey creates an atmosphere of fault finding;
- There is no of focus on continuous quality improvement;
- The survey process itself is intrusive in the lives of people with mental retardation.

These observations are consistent with many of those made in articles on ICF/MR regulation such as Boggs (1992), Dillon (1992), Kennedy (1990), Holburn (1992), Shea (1992), and Taylor (1992). As noted above, however, no empirical studies on the effects of active treatment quality assurance were identified.

Similar reports of constraints on contemporary practice were are found in comments by members of the Technical Working Group and related national organizations. For example, a July 14, 1994 letter from the American Network of Community Options and Resources (ANCOR), an organization representing service providers, including ICFs/MR, to Anthony Tirone, director of HCFA's Office of Survey and Certification, Health Standards and Quality Bureau, included comments on the need to redefine the term "active treatment," as well as concerns about an earlier (1994) approach to Facility Practice Statements and a matrix for compliance decision-making (Savejic, Johnson & Fritz, 1994). In 1995 an ANCOR task force on ICFs/MR indicated that surveyors continue to focus on process and paperwork, there are difficulties in compliance when using person centered planning, and there is inconsistency with the support model (Gerowitz, 1995).

Although these kinds of perspectives may be based on the imposition of State and local standards and/or on surveyor misapplication of the Federal standards, they contribute to perceptions that the ICF/MR program standards are inconsistent with contemporary concepts and approaches.



## **Active Treatment and Person Centered Planning**

ICF/MR surveyors, providers and program agency staff believe that the ICF/MR active treatment regulations can (and should) be made to accommodate best practice efforts. At its origin, active treatment was designed to provide stimulation and ongoing activity for consumers who otherwise were left to sit alone for long periods of time; it was also geared to young people who had been institutionalized much of their lives and needed significant intervention to increase their life skills. Because much of the field has moved far beyond this custodial model, and because the ICF/MR population is now substantially older, many surveyors and ICF/MR facility managers feel that the prescriptiveness of the regulations needs to be reduced and/or modified.

One of the major issues for ICF/MR facilities moving to best-practice approaches is laying out in advance the full ramifications of the new practices in the context of active treatment -- in short, knowing how to cross-walk between active treatment regulations and the new approach. Person-centered planning is a prime example. It offers much that is desirable within the active treatment context -- a greater role for consumers and family members (W209), attention to the individual increasing his/her self-determination and independence (W196, W240, W247), and so forth. However, other key components of person-centered planning are more problematic to conceptualize within the active treatment framework, such as the strong focus on consumer-preferred long-range goals and the development of natural supports in the community. A survey team member in one state summed up the problem by saying that "the problem is that person centered planning doesn't cover all the requirements (the tags) that are part of active treatment."

ICF/MR surveyors highlighted a key difference between the active treatment planning process and the person-centered planning process: the relationship between needs and goals and activities on the other. In active treatment, the starting point is the individual's needs, as identified through the comprehensive functional assessment; these needs in turn should be tied directly to the goals and objectives listed in the IPP; finally, these objectives should lead clearly to the daily activities of the individual. By contrast, the person-centered planning process begins with identifying the individual's goals and objectives, and laying out activities that will enhance achievement of the goals. In applying person-centered planning in an active treatment context, the goals must be translated into specific needs that, in turn, are addressed through particular objectives and thence through specific activities. Surveyors expressed support for the practice of beginning with goals, but struggled to find evidence that any subsequent link was made to needs or to activities. Their experience showed that person-centered planning left the arena of activities wide open. For example, what do you do when

staff offer consumers choices but do not support them to developing choice-making skills or to understand the consequences of their choices. What should you do when staff support consumers to participate in community activities but do not assist them to develop appropriate behaviors that would make them more accepted by other community members. These shortcomings could be remedied, as the surveyors have suggested, by some clear thinking about needs and short-term objectives and measurement of progress. The situation could also be addressed by more thorough training and mentoring on the support model, in particular around support/training strategies to help individuals develop needed abilities.

There have also been differences in the experience of specific ICFs/MR that have instituted person centered planning and the review of active treatment during surveys.

In one instance, a state facility in Oregon with a strong person centered planning program had problems meeting active treatment requirements. Surveyors cited a lack of formal assessments and related inability to measure progress. In Utah, however, surveyors and facility administrators indicated that person centered planning fits within active treatment regulations. Similarly, an administrator/QMRP at a State facility in Texas reported that their use of personal futures planning, a common focus of person centered planning, has not been a problem in recent surveys.

### **"Continuous Active Treatment" and "Over-programming"**

One of the recurring criticisms of active treatment has been that interpretations during surveys (or in anticipation of a survey) can lead to over-programming. This concern was heard among State program agency officials as well as providers. For example, one State official commented that when active treatment is expected to be aggressive, it is sometimes interpreted as requiring constant staff-client interaction, rather than recognizing that clients need down time. Another observed that "continuous" was being interpreted as requiring programming all day long even when it was meaningless to the individual. A facility administrator in Florida provided the following example:

During a recent survey, the [survey] team required that K.S. be given a formal goal related to her production at the day program where she is employed. Vocational skills had not been identified as a barrier for her by the Interdisciplinary Team. In fact, K.S. was fully integrated into the day program and was able to compete any task which was assigned to her. She continued to require the close medical supervision provided at the program and therefore was not at that time a good candidate for a vocational placement in the community. Communication skills had been



identified as a barrier for her, and she was making significant progress in formal programming in this area. The team would not accept a communication related program implemented in the work setting. The result was that K.S. was given a formal goal, related to her production abilities and because of the dynamic nature of available work at the day program, a somewhat artificial practice task had to be given to her for a program, preventing her from participating naturally in the day's activities, as did her peers from other facilities. This issue was taken to the HCFA Regional Director who supported the surveyor in spite of all our attempts to have HCFA understand our position. In the end, the citation was not revoked.

Although this reflects a misapplication of the regulations, the reality was a less desirable program for K.S. and a citation for the ICF/MR.

Another widely reported concern has been that "continuous active treatment" does not allow people to retire, despite guidance in *Appendix J* at W196 and W211 on active treatment for elderly individuals clearly indicating an age-appropriate focus. HSRI did not, however, find any specific examples of this concern.

### **Active Treatment and Making Choices**

State program agency staff and providers in several States voiced concerns about restrictions on consumer choice and decision-making. The project team contacted providers in approximately six States, in order to develop more specific examples of conflicts between the regulations and choice. Although some examples illustrate problems with regulations other than the Federal standards, such as the California Nintendo game issue cited above, others seemed to stem from Federal ICF/MR standards. The examples that were identified, however, were not necessarily relevant to the standards on active treatment. For example, a QMRP in a Maine facility reported problems regarding choice and medication reduction:

There have been instances when a consumer did not feel comfortable with medication reduction, but a decrease was clinically indicated. In both cases which come to mind, the IDT supported their decision but the facility still received deficiencies. Case #1: An individual with a borderline IQ and significant mental health issues, who had undergone reductions (just prior to, but not within the last 365 days) and was informed about her medication side effects; Case #2: A person receiving



Tegretal for seizure activity and behavior management as documented by a physician. The individual clearly expressed concern that a reduction could result in seizure activity. People appear to have difficulty recognizing the difference between medication used to "manage behaviors" and those prescribed to address the symptoms of a psychiatric disorder (as was the case in Case #1). There have been cases when the IDT reluctantly recommended a medication reduction in order to meet the regulations with poor results. In one instance, it took re-prescribing medication (even more than before), and months for the person to stabilize.

Another area mentioned by several provider respondents had to do with the nutritional guidelines regarding the timing of meals and the resulting constraints on choice regarding the schedule and location of eating meals. If individuals eat breakfast at 7:30 a.m., then they must eat dinner by 5:00 p.m. -- not usually the time most people want to go out to dinner and enjoy the company of friends. Further, on weekends, when people want to rise late and eat a large brunch -- instead of breakfast and lunch, this choice is precluded.

Although there are some areas of the regulations that directly affect choice (e.g., the timing of meals), most of the providers reported that the abridgment of choice, such as the examples noted above, were more the result of surveyor interpretation. One provider from Ohio noted that after working with surveyors over the years, they came to understand the larger goals of integration and choice and became more flexible in their judgments. There is also support for consumer choice in guidance at W247 on opportunities for client choice and self-management that emphasizes self-determination. These guidelines note that "due to the basic underlying importance 'choice' plays in the quality of one's life, the ICF/MR should maximize daily activities for its individuals in such a way that varying degrees of decision-making can be practiced as skills are acquired." Choice also is referenced in guidelines to W250, stating that "individuals should have opportunities to choose activities and to engage in them as independently and freely as possible."

Additional support for an emphasis on choice is found in the Compliance Principles for W122, the CoP for client protections. References to choice and supports for increased choice and self-determination are weak, however, in the Compliance Principles for W195, the CoP for active treatment. Although lack of opportunities to make choices in daily routines is part of one indicator that the active treatment CoP is not met, there is no affirmative principle on the importance of individual choice.

## Active Treatment Compliance and Outcome-Based Accreditation

Another area of inquiry concerned the compatibility of ICF/MR active treatment quality assurance with outcome-based accreditation systems. Provider respondents with experience with both approaches believe that the active treatment regulations and the Accreditation Council (AC) outcome standards share two basic characteristics: both make reference to the contemporary values of self-determination and choice, age appropriateness and cultural sensitivity, and community-based activities; and both recognize the importance of training and teaching to improve the lives of people with developmental disabilities. However, beyond this commonality in orientation, the two processes are seen to differ dramatically, to the point where one may interfere with the successful pursuit of the other. Fundamental to their conflict is the *difference in approach to quality*. The active treatment regulations are perceived as focusing on forcing facilities to follow certain practices and requiring certain behavior, while the premise of the AC standards is that organizations must facilitate good outcomes by allowing a range of desired practices to occur.

This same contrast -- quality control as opposed to quality enhancement -- carries through to the ways in which an individual's activities are structured. Active treatment requires consistency, careful scheduling, and a distinct link between the individual's daily activities and the objectives in his/her Individual Program Plan (IPP). AC standards, on the other hand, look more for flexible, individualized activities that are tied to a person's preferences, as long as the preferred activity contributes to alleviating, and does not aggravate, the person's problems or needs.

In similar fashion, the fundamental difference in approach between active treatment regulations and AC standards results in contrasting decision-making processes. Since active treatment means particular practices must occur, and that each activity is tied to a specific objective in the IPP, *professionals are needed* to assure that things occur in the prescribed way. By contrast, the AC standards, in allowing for flexibility and differences among people, foster a sense of openness to alternative objectives and activities, and look first to the individual to make decisions, as well as to non-professionals with a personal connection to the individual, recognizing that these people are important "quality assurance agents."

Some specific examples may be helpful in clarifying the way that active treatment regulations appear to interfere with the ability of a facility to attain Accreditation Council approval. Included here are insights from facilities that are striving toward AC accreditation and one which has been AC accredited.



- The *professional bias* in active treatment requirements is most apparent in the assessment and planning tags. The requirements for the Interdisciplinary Team (IDT) in terms of composition (W206-210) and responsibilities (W211-239) make assessment and planning the domain of the professional. Significant attention is given to establishing a linear connection between an individual's needs/deficits as identified in the comprehensive functional assessment, and the IPP objectives, and thence to specific program activities (see especially Survey Procedures IXC, 1988 version). This practice puts the professional in the key role of justifying each activity that the individual engages in, in terms of professionally-determined needs and plan objectives. The actual planning meetings may well include very active individuals and family members, but professionals take responsibility for gathering the assessment information (which is used in deciding what objectives to set) and in arraying the possible program activities (which will address the objectives).

A few facilities have explored various avenues to minimize the problem of professional dominance. Two of the more successful strategies have been to decrease the role of specialists in service provision, and to increase the interdisciplinary focus of the IDT. As direct care staff take on more responsibility for physical and occupational therapy tasks (although these are still designed by the PT or OT), they are more able to assert the consumer's wishes and strengths into the planning process; this works best where staff have a long-standing relationship with the consumer. Similarly, IDT members are urged to rely heavily on consumer observation and interviewing as they develop the needed assessments, and are expected to present their own "piece" in the context of the whole of the consumer's life, thus giving greater consideration to consumer preferences and unique personal characteristics. In essence, these facilities have influenced the professional viewpoint so that it reflects more of the consumer perspective, rather than trying to alter the power balance directly.

- The emphasis on having and following a *detailed activity schedule* implies a rigidity in activities, despite interpretive guidelines that suggest otherwise. For example, guidelines for W250 say "the schedule provides a range of options, rather than a fixed regimen" and that the individual should experience "reasonable choices." However, surveyors are only directed to investigate further when they observe all individuals doing the same activities -- protecting against the problem of one schedule being imposed on all residents, but not highlighting the equal problem of a single individual being unable to change his/her schedule on short notice, which is a more normalized pattern of behavior. Indeed, the 1988 version of *Appendix J* that was in use in the field until December 4, 1995, when a revised version became effective, includes



probes that question why an individual is not following the prepared schedule, specifically, "what is the individual doing when not 'on task'? "for how long?"

All facilities have to maintain the 24-hour schedule for consumers, but some are more willing than others to make last-minute changes in any one person's schedule. The key seems to be if staff feel that they have the autonomy to make such person-centered changes, and that they will be supported by their supervisors, should any questions come up. Also important is having some flexibility in staff assignment/availability to be able to accommodate each consumer's wishes.

- *Limitations on choice and individual preferences* occur throughout the active treatment regulations, but are perhaps most evident for the dietetic services condition of participation. Tags under "meal services" include a requirement of at least three meals daily (W467), at regular times not to exceed certain hourly limits (W468-471); menu requirements prohibit frequent repetitions of the same food (W478-479), although the probes encourage flexibility as long as nutritional value is comparable; and the dining areas standard requires individuals to eat in the dining area unless the physician or the IPP documents the necessity of doing otherwise. In the experience of State facilities, these tags mean that the individual is limited in when, where, and what he/she eats, even though these limitations do not directly increase life quality and may even decrease it. Regulations such as these were designed to remedy gross problems such as denying people food or not giving them a balanced diet, but in current practice can seriously limit the goals of choice and individualization. Other tags foster the use of centralized kitchens, laundry, and pharmacy services, because of the necessity to ensure control of specific compliance issues..

Even facilities that do not see these tag limitations as *significant* barriers to consumer choice agree that they can be problematic. Again, their strategies stem from a willingness to "stretch" definitions and interpretations, such as designating numerous "dining areas" to allow choices of where to eat, as well as a willingness to complicate the responsibilities of supervisory staff (e.g. the director of nutrition services sets menu selections for the central kitchen, but also oversees the food shopping list and menus used by a small group of residents who prepare their own meals).

Similarly, State facility administrators in a State with an outcome-based licensure system modeled after the AC standards reported some differences between the State's quality assurance program and ICF/MR quality assurance:

Expectations conflict between [the State's outcome-focused quality assurance system] and ICF/MR quality assurance. The ICF/MR survey cited wandering in the hallway, while [the outcome-based survey] said that not enough people were wandering in the hallways. ICF/MR regulations do not permit [client] rooms to be locked, yet maybe the individual needs privacy. ICF/MR rules won't permit sharing of soap, but [the outcome-based survey] encourages a family atmosphere. Both systems have a problem with imposing value systems. For example, we can be alone [if we choose], but these systems might force someone to "integrate." The difference is that ICF/MR quality assurance would force integration, but [the outcome-based quality assurance system] would look at what supports you've offered.

The major factor that enables ICF/MR facilities to reduce the conflicts between active treatment regulations and outcome standards is the meaningful embrace of the outcome philosophy. Training is reported to be crucial, as is continued mentoring among staff and consistent support from supervisors and administration in a facility. Staff longevity is also important. Where staff, especially direct care staff, have been in the job for a number of years, and have established meaningful relationships with consumers, they tend to be more open to explicitly focusing on consumer outcomes, and may have already been "stretching" the active treatment regulations to fit an outcome emphasis. Ultimately, however, facility staff at all levels have to know that the ICF/MR surveyors adhere to the outcome philosophy and will be open to interpreting the regulations in a way that is most meaningful to consumers. Some surveyors are willing to discuss the particular situations with facility staff, so they understand more fully what is occurring. This process often reduces the problem to one of documentation, which can be more readily resolved without altering the activities for the consumer.

## Survey Procedures

The focus on outcomes, person centered planning and supports to reach personal goals lends itself more to the type of survey HCFA has developed this past year and is currently promoting through the revised survey procedures in the *Appendix J* that will become effective July 1, 1996, for implementation by the States no later than October 1, 1996. The features particularly consistent with contemporary concepts include:

- The priority given to observations and interviews, including both the individual and direct care staff;



- The use of a Fundamental Survey scaled back to focus on essential rights and services;
- Most of the active treatment tags selected for the Fundamental Survey.

The guidance regarding full surveys is largely unchanged from the 1988 version except for the Compliance Principles and Facility Practice Statements. In the absence of additional guidance, for example regarding the appropriateness of person centered planning in IPP development, and the use of the support model as the basis for "active treatment," traditional interpretations and misapplications of the ICF/MR standards may occur.

Surveyors also may require more support on the effective use of interviews, especially in interviewing individuals whose verbal ability is very limited or non-existent. As indicated in HSRI's comments on *Draft No. 6 Revised Survey Procedures* (see F), this is an area that HCFA may want to strengthen.

### **Active Treatment and Utilization Review**

During the course of its investigation, HSRI received scattered reports that the review of active treatment in conjunction with the Independent Professional Review/Utilization Review (IPR/UR) process is more inconsistent with contemporary concepts than the ICF/MR survey. There is no consensus on the extent of the problem, however, due to the wide variation among the States on how IPR/UR is carried out in relation to the ICF/MR survey. In many States, IPR/UR is done in conjunction with the ICF/MR survey, by the ICF/MR surveyors. ICF/MR providers may not even be aware that a separate process has occurred. In other States, however, IPR/UR is done separately. In States where the procedures are blurred, providers may assume that the paperwork-focused IPR/UR review is part of the ICF/MR survey.

Unlike the ICF/MR standards and guidelines, it is our understanding that IPR/UR regulations have not been changed since 1979. They seem to reflect the opposite of HCFA's current ICF/MR survey focus on outcomes and primary use of observations and interviews. Because the active treatment standards require that ICFs/MR provide continuous active treatment (W196) and do not as a practice serve individuals who are not in need of continuous active treatment (W197), the IPR/UR review also is considered duplicative by some State program agency administrators.



## DISCUSSION

Although the ICF/MR active treatment regulations can be made to accommodate best practice, and to allow individuals to obtain the amount and variety of supports they need and want, this does *not* mean the existing regulations should not be changed. Ideally, active treatment regulations would *foster* positive consumer outcomes, rather than just allow them to occur. Fundamentally, the prescriptiveness of the current regulations needs to be reduced. This has been addressed somewhat through the interpretive guidelines and the probes offered in the December 1995 version of *Appendix J*, but even that leaves surveyors and program managers attending to minor details at the expense of addressing the overall quality of a person's life.

There is strong consensus that custodial care is inappropriate, and that some degree of regulation is necessary. As summarized by Taylor (1992) regarding the cross-section of articles cited above, none of the contributors advocated doing away with all regulations. Similarly, none of the knowledgeable individuals across the States whom we spoke with and no members of the Technical Working Group, to our knowledge, advocate total deregulation of the ICF/MR program regarding the provision of services and supports. It is also understood that the term "active treatment" is provided in statute governing the ICF/MR program, and therefore that the term must be retained in some form in revised regulations.

HCFA's actions over the past several months, as well as actions underway as this report is being prepared to bring updated training to ICF/MR surveyors nationwide, are clearly steps in the right direction. The first informal draft of revised ICF/MR standards circulated spring 1996 reflects approaches that are more consistent with contemporary approaches and the primary outcomes. Given the likelihood that it will be a few years before revised ICF/MR regulations are final, however, there are some steps that HCFA can take to make current standards, guidance and survey procedures more consistent in the interim.

Overall, it appears that key elements consistent with the primary outcomes and with a supports model are present in current regulations and guidance. The Compliance Principles for the active treatment CoP describe outcomes of increased skills and independence in functional life areas, one of which is use of community, and indicate that the CoP is not met when individuals are not involved in activities which address their individualized priority needs or do not have opportunities to practice new or existing skills and to make choices in their daily routines. Because the developmental approach is still so prominent, however, the scattered references to choice, self-

determination, community involvement, and relationships get lost, especially in the review of active treatment. In particular, despite a few references to choice, there are no explicit references to active treatment based on the goals that are important to the individual.

Further, while the new Facility Practice Statements at W213 on identifying developmental strengths in order to include clear descriptions in the CFA of the individual's preferences, methods of coping/compensation, friendships and positive attributes is a step forward, it is offset by tag W214. That tag on developmental and behavioral management needs calls for descriptions of individual needs, skill deficits and functional limitations. In addition, Facility Practice Statements at W227 (one of the 15 tags included in the Fundamental Survey on active treatment) require that the IPP contain a list of specific objectives based on needs identified in the CFA, a clear link between the specific objectives and the functional assessment data and recommendations, along with objectives for those needs that are observed to most likely impact on the individual's ability to function in daily life. Guidelines imply a requirement that objectives must be stated for the needs identified in each domain included in the CFA, with no mention of objectives selected because of their importance to the individual's attainment of personal goals.

In addition, the December 1995 revisions to *Appendix J* strengthen the active treatment focus on the acquisition of skills in activities of daily living (ADLs). This is particularly noticeable in the Facility Practice Statements and Guidelines at W242, which makes the list of "personal skills essential for privacy and independence" in current ICF/MR regulation (s483.440(c)(6)(iii)) the basis for required training programs for all individuals who lack the skills listed, and describes "the receipt of training targeted toward amelioration of these most basic skill deficit areas" as a "critical component of the active treatment program needed by individuals who are eligible for the ICF/MR benefit" that therefore "is a required ICF/MR service." The revised Guidelines further state that it must be clear "that the facility has organized its services to emphasize training in these areas." The overall impression left by these statements is that active treatment is primarily about deficits in ADL skills, not about primary outcomes such as community integration and inclusion, relationships, and self-determination. This appears inconsistent with the introduction to survey procedures in the July 1996 revisions to *Appendix J*, which indicates that facilities are being given "broader latitude to develop the processes by which it implements active treatment services."

As noted above, some criticisms of the standards and the survey process appear to be the result of State and local regulations that go beyond Federal requirements or of



misapplications of Federal standards. Training and dissemination that includes ICF/MR managers as well as surveyors may reduce these misunderstandings.

## IMPLICATIONS AND RECOMMENDATIONS

### Suggestions for Near-Term Activities

There are implications for revised definitions, standards and survey design that would help bring ICF/MR quality assurance more in line with contemporary values and approaches to supporting individuals with mental retardation/developmental disabilities. In the short-term, HCFA should consider the following activities to continue its move in that direction:

#### *Training/Training Support*

1. Clarify that person-centered planning and personal futures planning can be the basis for the IPP and for the active treatment being provided -- couched in terms of the CFA, if necessary -- and provide written guidance on how to crosswalk these planning approaches with the current regulations.
2. Include training on person-centered planning itself, using resources such as Michael Smull of the University of Maryland (recommended because of his experience with large State facilities as well as community residential service clients).
3. Clarify that the support model can be active treatment, coupled with revisions to Facility Practice Statements and Guidelines at W242 to indicate that skill building and behavioral objectives related to ADLs are a component of active treatment, but not the only one. This is consistent with the introduction to survey procedures on page J-2 of the revision effective July 1, 1996, as well as more consistent with contemporary practice.
4. Continue the training on observations and interviews to determine active treatment compliance, with expanded coverage on the use of observations and interviews with and in relation to individuals whose communication modes are limited or primarily non-verbal.
5. Include examples of promoting choice and providing supports to self-determination, relationships and community participation for individuals in large institutional ICFs/MR, and reinforce surveyors' expectations that these



primary outcomes are not just for individuals in smaller community-based ICFs/MR.

6. Reinforce the clarification on retirement as an appropriate active treatment option for older individuals.
7. Review the training video about to be distributed to be sure it is consistent with these approaches.
8. Work with Regional Office staff to identify ongoing needs for training and technical assistance, especially in States where surveyors review a relatively small number of ICFs/MR.

### *Revisions and Addenda to Appendix J*

1. Revise the Compliance Principles for the active treatment CoP (W195) to move involvement in activities to meet individualized priority needs and opportunities for choice to the principles governing when the CoP is met.
2. Rephrase guidance on "continuous" to reinforce the emphasis on consistency and coordination, clarifying that this does not mean "every waking moment."
3. Revise Facility Practice Statements and Guidelines for the CFA and IPP to include person-centered planning as a desirable approach to the development of active treatment programs. Provide a specific crosswalk between person centered planning/personal futures planning and existing regulations on the CFA and IPP.
4. Provide guidance on expectations for ICFs/MR in understanding the communications of people with severe disabilities and understanding and honoring their choices.
5. Include in the Facility Practice Statements questions on determining people's preferred lifestyles and in providing services consistent with their preferences.
6. Add person-centered planning and related concepts to examples of in-service training to look for (W189) and demonstration of staff skills (W194).
7. Revise the list of suggested interview questions and guidance on interviewing individuals to incorporate diverse and less complex communication that is more appropriate to people with severe cognitive disabilities. Emphasize the

importance of talking with those who know the person best, including direct care staff in particular, and family members/friend advocates as appropriate, as well as the individual.

8. Consider that attendance at IPP planning sessions is not the only way individuals participate in IPP development. Although surveyors should question how the individual's goals, wishes, preferences and priorities were central to IPP development and review of progress, physical attendance at the meeting is not always the best method.
9. Modify Facility Practice Statements and Guidelines at W242 as indicated above.
10. Cross-reference relevant standards and guidance in other parts of the regulations, in particular Compliance Principles for W122, the CoP on Client Protections; Facility Practice Statements for W125 on teaching and encouraging individuals to claim and exercise their rights; related Facility Practice Statement at W267 on helping individuals to learn and exercise their rights; Compliance Principles for W266, the CoP on Behavior and Facility Practices; and Facility Practice Statements at W269 that are strongly focused on the key role preferences and choices should play.
11. Include W122, W266 and W269 in the Fundamental Survey.
12. Cross-reference recommended revisions on the CFA and the IPP to W159 on QMRP responsibilities and to W164 re: needs for professional services.
13. Although guidance at W136 includes references to community participation that are consistent with the primary outcome, it needs to be stronger on choice. We recommend adding guidelines similar to those at W147, which include choice in relation to outings.
14. Examine the 1992 AAMR definition of mental retardation for its elucidation of the support model (i.e., not necessarily in relation to defining eligibility for ICF/MR services). See, for example, the forthcoming August 1996 issue of *Mental Retardation*, which will include guidelines for defining levels of support.

### ***Research and Technical Assistance Support***

1. Conduct organized "feedback analysis" of surveyors and public and private ICF/MR providers from October 1, 1996 - September 30, 1997, and use it to

guide training, technical assistance, research priorities, interim revisions to *Appendix J*, and revisions to ICF/MR regulations.

2. Develop HCFA's ICF/MR program role as a "Center for Excellence" on quality assurance.
3. Identify resources on quality assurance appropriate to the ICF/MR program and disseminate information on them to State ICF/MR quality assurance programs.
4. Incorporate findings from the Minnesota quality assurance demonstration program, the Accreditation Council research project, and others, including State data collection and analysis projects, as appropriate.
5. Develop a research agenda on quality assurance methodologies and on outcomes based on a person centered planning/individual supports model.
6. Examine research recently conducted by Conroy (1995) comparing outcomes for matched pairs of individuals in ICFs/MR and non-ICFs/MR, considering potential replication and implications for revisions to ICF/MR quality assurance.
7. Continue to refine and disseminate training resources.

### *Consensus Building*

1. Continue plans to encourage States to bring providers and surveyors together in training sessions on revised survey procedures.
2. Continue wide dissemination of further refinements of the proposed revised standards.
3. Circulate proposed interim revisions to *Appendix J* for informal review and comment among stakeholders.
4. Promote dissemination of the Task A Final Report, this report, and the Task B Final Report for this project.
5. Continue plans to convene focus groups of stakeholders, coupled with cross-cutting groups at key points in decision-making.



## **IPR/UR**

1. Continue efforts to eliminate IPR/UR regulations as redundant.
2. In the interim, consider issuing guidance to the States cross-walking IPR/UR with relevant portions of *Appendix J with revisions as suggested above* (i.e., indicate connection to survey findings at W196 and W242, but only with revisions to clarify that active treatment is more than building ADL skills).

## **Activities for the Longer Term**

### ***Revised ICF/MR Standards and Survey Procedures***

HSRI has submitted comments on the informal draft revisions of March 1996 (see Appendix D). Our assessment is that they reflect a positive effort to consolidate standards, reduce confusion, and incorporate the primary outcomes -- at least up to a point. The format is consistent with our suggestion that relevant processes that promote valued outcomes be included. For a re-defined and re-oriented active treatment application, this suggests that surveyors look at the involvement of individuals and those closest to the individuals in defining what is important, what the consumers hope to get from ICF/MR services, what kinds of supports are most helpful, and what is affecting the move toward consumers' personally desired outcomes, whether positive or negative. This is consistent with the approach taken by the Accreditation Council in its 1992 standards, which includes review of the processes as well as the outcomes they relate to.

To bring the revised standards even more in line with contemporary concepts, we specifically recommend the following definition of active treatment:

#### **Individualized Services and Supports (Active Treatment) Definition.**

(1) Each individual must receive individualized services and supports (active treatment) based on personal goals, preferences and needs. The individualized active treatment program must be implemented consistently and include services and supports needed by each individual to:

- Develop increasing skills, especially those that promote greater independence, self-determination, and achievement of goals important to the individual;

- Develop and maintain satisfying relationships;
- Participate in community life;
- Exercise rights and responsibilities;
- Engage in productive activities; and
- Enjoy and participate in social, leisure and recreational activities.

(2) Active treatment/individualized services and supports must prevent or decelerate regression or loss of current optimal functional status.

(3) Active treatment does not include supports or services to maintain generally independent individuals who are able to function with little supervision or in the absence of an active treatment program [same as proposed #2].

"Active" can be defined to mean the provision of supports and services, as opposed to custodial care, and "treatment" should be clarified to encompass a variety of supports and services, not limited to professional services or to those provided by and in the ICF/MR. "Continuous" could be redefined to mean an ongoing, flexible program of individualized services and supports, emphasizing that this does not mean "every waking moment" interventions.

HSRI recommends putting the following as the first active treatment outcome:

Each individual receives individualized services and supports (active treatment program) that is based on their person-centered plan, in which the individual and those who know him/her best have identified personal goals and the services and supports needed to reach those goals.

We also recommend that proposed outcome #6, on individuals identifying and working toward the accomplishment of personal goals, follows this outcome.

Regarding Active Treatment Facility Processes, we recommend that the first process (revised from proposed #4) be as follows:

The facility implements a system to ensure that individual personal goals and desires are identified and form the basis of his/her plan of services and supports.

We also recommend adding, at the end of proposed process #7, "and to reduce the need for behavior management programs," as well as adding the following new process:

Supports are provided to help individuals develop and maintain relationships, to increase their participation in community life, and to have experiences that increase their ability to make choices.

We recommend revising proposed process #10 as follows:

The facility ensures that individual plans are modified or changed in response to the individual's specific accomplishments, changes in individual goals and preferences, need for new programs, or difficulties in acquiring or maintaining skills.

It is also suggested that the comprehensive functional assessment and IPP be replaced with person-centered planning/individual support plans, without prescribing a particular model. Person-centered planning concepts could be included in standards and in guidance to surveyors on what to look for in personal futures planning and other similar models that start with what's important to the individual rather than what a team of professionals think is important. For example, personal futures planning:

- Is based on a positive view of people with disabilities, rather than seeing them as having "defects" and impairments to be "fixed;"
- Is comprised of goals that anticipate that positive changes, activities and experiences will increase, rather than focusing on decreasing specific negative behaviors;
- Uses ideas and possibilities for community sites and settings, and valued roles in those settings; and



- Includes goals that are important to the individual even if some of them seem outlandish, unrealistic, and impractical or require major changes in existing patterns (adapted from Mount, 1994).

An example of a generic approach to such planning, developed by Michael Smull and distributed at the Technical Working Group meeting on December 11-12, 1995, is presented on the following pages.

## An Outline of New Support Planning Format

A new process can be seen as a series of questions and answers, assessment and outcomes. For people with extensive support needs an outline of the new process would be:

TABLE 2

### PERSON CENTERED PLANNING

Assessment	Learn how the person wants to live
Outcome	Prioritized description of how the person wants to live
Assessment	Determine if there are any issues of health or safety in the context of how the person wants to live
Outcome	Description of how issues of health and safety will be addressed in the context of how the person wants to live
Assessment	Compare how the person lives now with how they want to live
Outcome	<p>For those aspects of the person's life that are congruent with how they want to live - a description of how those aspects will be maintained</p> <p>For those aspects that are not congruent with how they want to live - a description of what can be changed in the short term (and how it will be changed) and what will take time (and what will be done). Financial limitations/cost barriers will be identified and addressed here.</p>
Assessment	<p>Within the context of maintaining those things that are congruent and changing those that do not -</p> <p>What does the person want to learn and how can it be taught?</p> <p>What do the people supporting think that the person needs to learn, is the person interested in learning it, and how can it be taught?</p> <p>What support and/or assistance does the person need and how will it be provided?</p> <p>How will the people implementing the plan know if it is "working", what are the verbal and/or behavioral indicators that change is needed?</p>
Outcome	<p>An individual support plan that:</p> <ul style="list-style-type: none"><li>· describes what will be done and who will do it</li><li>· is written in language that the people implementing understand</li><li>· documents that the outcomes are occurring; and</li><li>· documents how well the plan is working</li></ul>

There should be a relationship between the amount of support that a person wants and requires and the length and complexity of the plan. For people with few support needs the planning process should be simpler. For those people who are quite clear about what they want and do not want from the system it might consist of a process as follows:

**TABLE 3**

**PROBES: PERSON-CENTERED PLANNING**

Assessment	Ask the person what they want from the service system
Outcome	A description of the services that the person wants
Assessment	Determine if there are any issues of health or safety in the context of how the person wants to live
Outcome	Description of how issues of health and safety will be addressed in the context of how the person wants to live
Assessment	How can the desired supports be best provided given - How the person wants to live and The community and service system resources
Outcome	An individual support plan that: <ul style="list-style-type: none"> <li>· describes what will be done and who will do it</li> <li>· is written in language that the people implementing understand</li> <li>· documents that the outcomes are occurring; and</li> <li>· documents how well the plan is working.</li> </ul>

Source: M. Smull (1995).

***Survey Procedures***

The need for new approaches suggests that HCFA is on the right track in emphasizing observation and interviews over record review in its revised survey protocols piloted



spring 1995. Two specific suggestions, also provided in HSRI's review of the draft revised protocols, are as follows (see Appendix D for full comments):

- Include interviews with direct care staff as a major component in reviewing the extent to which individuals have individual support plans that are, in fact, person centered, and the extent to which they are reaching their personally desired outcomes.
- Provide extensive guidance (and related training) on how goals, preferences, aspirations, and so forth, are communicated by those with severe communication disabilities.

States that have moved to outcome-focused quality assurance systems report that these are areas that warrant particular attention.

### ***Reliability and Validity***

As draft standards and related survey protocols are developed, we recommend that pilot tests be conducted to assess reliability and validity. Like the analysis recently conducted by the HSRI project team for HCFA on State outcome-based quality assurance systems, tests should include applicability across settings (e.g., size of ICF/MR), concurrent validity, and discriminative validity, as well as reliability.

### ***The 1992 AAMR Definition of Mental Retardation***

HCFA may want to consider referencing the new (1992) definition of mental retardation adopted by AAMR, which incorporates the concept of supports as an integral component of the assessment process, along with the concept of five valued accomplishments: 1) community presence; 2) choice, autonomy and control; 3) competence, including the opportunity to express one's gifts and capacities; 4) respect and having a valued place in one's community; and 5) community participation/network of personal relationships (Luckasson and Spitalnick, 1994). As developed by AAMR, supports relate to these desired accomplishments as follows:

Supports refer to an array, not a continuum, of services, individuals, and settings that match the person's needs...[and] should be matched in the context of the person's desires. Supports are resources and strategies that promote the interests and causes of individuals...that enable them to secure access to resources, information and relationships as part of

inclusive work and living environments and that result in enhanced interdependence, productivity, community inclusion, and satisfaction. Support resources are individual resources, skills, and competencies and the ability and opportunity to make choices, manage money, manage information, and the life. These resources are also other people, whether family, friends, coworkers, people one lives with, mentors, or neighbors. Technology might also be a form of support resource and includes assistive devices, job or living accommodations, or even behavioral technology. Another support resource encompasses habilitation services that may be needed if the other naturally occurring resources are either not available or not sufficient to assist the person in a desired living, working or school environment. Clearly, these services, whether provided by a specialized disability agency or a generic service agency, are a subset of supports (Luckasson and Spitalnick, 1994).

As indicated above, this is not recommended as an alternative to the current eligibility definition for ICF/MR services. HCFA may want to consider, however, the implications of revising the eligibility definition to include a subset of those with support needs. (See the forthcoming article in the August 1996 issue of *Mental Retardation* for a typology based on level of intensity of supports needed.)

### *Refinements in HCFA's Role in ICF/MR Quality Assurance*

HSRI has suggested that HCFA consider performance contracts with the States in ICF/MR quality assurance (see Task A Final Report). In relation to active treatment, for example, HCFA standards could define active treatment, set minimum requirements for its review, describe an array of quality assurance components for States to select in making ICF/MR quality assurance appropriate to their use of the ICF/MR program, approve State ICF/MR quality assurance plans, and oversee compliance with these plans through existing or modified "look behind" authority. The performance contract approach also recognizes that States' ICF/MR quality assurance needs vary, for example, States with only a few small ICFs/MR vs. States with a few very large State-operated ICFs/MR or States with hundreds of small ICFs/MR. This could be coupled with HCFA's expansion of its role (recommended above) as a Center for Excellence in quality assurance, and in sponsoring research and demonstrations on effective quality assurance.

We suggest that HCFA continue to refine the definition of active treatment and related guidelines based on the recommendations included in this report and that States be



allowed to meet certification requirements either through conventional surveys or through national accreditation that is consistent with HCFA's refinements.

The overall recommendations presented in the separate Task A and Task B reports encompass the future regulation of active treatment. These include the recommendation that HCFA develop a set of from 15 to 20 quality of life indicators based on the valued outcomes and that HCFA take the lead in developing and publishing national norms for these indicators, through periodic national surveys.

In addition, HSRI strongly suggests that HCFA explore the application of ICF/MR quality assurance recommendations on quality of life indicators, continuous quality improvement, external monitoring and publishing of quality assurance findings to the Home and Community Based Services Waiver program (1950(b)) as well as inclusion in the criteria for approval of 1115 Managed Care Waivers.

Because of the growing interest in Medicaid managed care for long term services to people with mental retardation/developmental disabilities, it is important that HCFA explore ICF/MR quality assurance issues under such a managed care benefit. Similarly, should States receive Medicaid long term care funds (or combined long term and acute care Medicaid funds) in the form of block grants, either on a demonstration basis or nationwide, HCFA will need to provide guidance on the maintenance of quality assurance for those currently in need of the ICF/MR level of care. This will be an essential role for HCFA to play, regardless of any future changes in their regulatory authority.





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**APPENDIX A**  
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## **APPENDIX B**

- 1 BEHAVIORAL DEVELOPMENT SURVEY**
- 2 HEALTH AND SAFETY ISSUES INSTRUMENT**





## BEHAVIORAL DEVELOPMENT SURVEY



# EVALUATION OF ICFs/MR

## BEHAVIOR DEVELOPMENT SURVEY

Developed by:  
Temple University  
Institute on Disabilities/UAP  
November 13, 1995

*Please Print*

Sequence # \_\_\_\_\_

Person's Social Security # \_\_\_\_\_  
\_\_\_\_\_

Person's Name \_\_\_\_\_  
Last First M.I.

\_\_\_\_\_  
Residential Provider

\_\_\_\_\_  
Complete Site Mailing Address

\_\_\_\_\_  
City, Town State Zip Code

\_\_\_\_\_  
Primary Respondent Name

( ) \_\_\_\_\_  
Telephone

\_\_\_\_\_  
Name of Data Collector



## DEMOGRAPHICS

1. TODAY'S DATE

\_\_\_\_/\_\_\_\_/\_\_\_\_  
Month Year

2. PERSON'S DATE OF BIRTH

\_\_\_\_/\_\_\_\_/\_\_\_\_  
Month Day Year

3. RESIDENTIAL PLACEMENT TYPE

☐

- 1 Public Institution (Not ICF/MR)
- 2 ICF/MR, 16 beds or more
- 3 ICF/MR, 4 to 15 beds
- 4 Community Living Arrangement, group home or apartment (30 hours or more of staff time per week)
- 5 Community Living Arrangement, group home or apartment (Less than 30 hours of staff time per week)
- 6 Supported Living (30 hours or more of staff time per week)
- 7 Supported Living (Less than 30 hours of staff time per week)
- 8 Home and Community Based Waiver Services (in-home)
- 9 Foster Family, Family Living Program
- 10 With Family or in own Home
- 11 Nursing Home
- 12 Other (Describe) \_\_\_\_\_

4. LEVEL OF RETARDATION  
(Please seek documentation)

☐

- 5 Profoundly retarded
- 4 Severely retarded
- 3 Moderately retarded
- 2 Mildly retarded
- 1 Not mentally retarded

5. OTHER DISABILITIES

Seek documentation. Enter code in box. Leave none blank.

- 1 Yes  
0 No  
9 Don't know

☐

Blind

☐

Mental Disorder

☐

Autism

☐

Cerebral Palsy

☐

Epilepsy, Controlled

☐

Epilepsy, Uncontrolled

☐

Non-Ambulatory, Mobile

☐

Non-Ambulatory, Non-Mobile

☐

Speech/Language Impairment

☐

Hard of Hearing

☐

Deaf

☐

Visual Impairment

Other Health Impairment (specify):

---

---

---

6. SEX

☐

- 1 Male  
2 Female

7. RACE

☐

- 1 White  
2 African-American  
3 Latino  
4 Asian  
5 Other

HEALTH AND SAFETY

MEDICATION:

1. How many medications does this individual take on a daily basis? Count each medication that is given to this person daily and that is prescribed. Do

not count vitamins or topical ointments.  
Enter the exact number.

\_\_\_\_\_

2. Is this individual receiving any medication for the purpose of behavior change?

☐

1 Yes  
2 No

3. If this individual is receiving medication for the purpose of behavior, has the prescribing physician certified the continuing medication within the past 90 days?

☐

1 Yes  
2 No  
9 NA

4. Has the person been screened for side effects of psychotropic medications? (Answer yes only if AIMS or DISCUS screenings are documented).

☐

1 Yes  
2 No  
9 NA - person receives no psychotropic medications.

**5. Results of medication screening.**

Does this person have any side effects resulting from medication as documented by the above listed screening tool? (AIMS or DISCUS)

☐

1 Yes  
2 No  
8 Unknown-AIMS or DISCUS not administered  
9 NA - person receives no psychotropic medications.

6. If this person receives psychotropic medication, does he/she have a psychiatric diagnosis?

☐

1 Yes  
2 No  
9 NA - person receives no psychotropic medications.

7. If this person receives psychotropic medication, does he/she have a formal behavior plan which seeks to reduce the use of this medication over time?

☐

1 Yes  
2 No  
9 NA-person receives no psychotropic medication



## MEDICAL NEEDS:

1. In general, how urgent is this person's need for medical care?

☐

- 3 Generally has no serious medical needs  
2 Needs visiting nurse and/or regular visits to the doctor  
1 Has life-threatening condition that requires very rapid access to medical care  
0 Would not survive without 24-hour medical care

2. How many times has this person seen each of the following doctors in the past year?

- \_\_\_\_\_ a. General Practitioner/Internist  
\_\_\_\_\_ b. Obstetrics/Gynecologist  
\_\_\_\_\_ c. Psychiatrist  
\_\_\_\_\_ d. Dentist  
\_\_\_\_\_ e. Podiatrist  
\_\_\_\_\_ f. All others

3. Has there been a problem getting medical care during the past year?

☐

- 2 No problem  
1 Minor or occasional problem(s)  
0 Major or frequent problem(s)

Describe the problem:

---

---

---

4. Has there been a problem getting dental care during the past year?

☐

- 2 No problem  
1 Minor or occasional problem(s)  
0 Major or frequent problem(s)

Describe the problem:

---

---

---

5. Has there been a problem getting mental health care during the past year?

- ☐
- 2 No problem  
1 Minor or occasional problem(s)  
0 Major or frequent problem(s)

Describe the problem:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

6. Does this person have an Individual Health Care Plan?

- ☐
- 1 Yes  
2 No

## UNUSUAL INCIDENT REPORTS

1. Have there been any unusual incidents involving this individual in the past 6 months that you have reviewed?

- ☐
- 1 Yes  
2 No

2. If yes, how many? (Enter exact number)

\_\_\_\_\_

3. For the unusual incidents you identified, please indicate how many of each type were reported.

- \_\_\_\_ a. Injury/illness requiring hospital admission  
\_\_\_\_ b. Serious illness requiring doctor  
\_\_\_\_ c. Medication error  
\_\_\_\_ d. Suicide attempt  
\_\_\_\_ e. Unauthorized absence - immediate jeopardy or more than 24 hours

- \_\_\_\_ f. Fire requiring fire department  
\_\_\_\_ g. Emergency program relocation  
\_\_\_\_ h. Alleged misuse of client funds or property  
\_\_\_\_ i. Outbreak of communicable disease  
\_\_\_\_ j. Alleged violation of client rights  
\_\_\_\_ k. Other (please specify)

4. For the unusual incidents you identified, please indicate how many of each type were reported.

- a. Rape (alleged) \_\_\_\_ Victim  
Rape (alleged) \_\_\_\_ Perpetrator  
b. Assault (alleged) \_\_\_\_ Victim  
Assault (alleged) \_\_\_\_ Perpetrator  
c. Abuse (alleged) \_\_\_\_ Victim  
Abuse (alleged) \_\_\_\_ Perpetrator  
d. Serious behavior incident: police involvement with a client specific incident  
\_\_\_\_ Victim  
\_\_\_\_ Perpetrator  
e. Serious behavior incident: emergency restraint  
\_\_\_\_ Victim  
\_\_\_\_ Perpetrator

5. Are there any instances of abuse, neglect, or mistreatment that have gone untreated? (Please look at 1 month's daily logs).

- ☐
- 1 Yes  
2 No

If yes, please describe:

\_\_\_\_\_  
\_\_\_\_\_

## BEHAVIOR PLAN

1. Does this person have a formal behavior plan?

☐

1 Yes  
2 No

2. Is there any evidence of use of physical restraints?

☐

1 Yes  
2 No

If yes, when did they occur?

---

---

---

3. If the answer to question 2 is yes, are the use of restraints part of a program plan?

☐

1 Yes  
2 No  
9 NA

4. Is there any evidence of use of Time-Out Rooms?

☐

1 Yes  
2 No

If yes, when did the use occur?

---

---

---

5. If the answer to question 4 is yes, is the use of the Time-Out Room part of a program plan?

☐

1 Yes  
2 No  
9 NA

6. Is there any evidence of the use of painful and/or noxious stimuli?

☐

1 Yes  
2 No

If yes, when did the use occur?

---

---

7. If the answer to question 6 was yes, is the use of painful and/or noxious stimuli part of a program plan?

☐

1 Yes  
2 No  
9 NA

8. Are there any unusual incidents that have not been reported? (Look for documentation)

☐

1 Yes  
2 No

Describe the incident:

---

---

---

## SAFETY

1. Are there adequate number of smoke detectors in this house/apartment /living area (one per floor including attic and basement)?

☐

1 Yes  
2 No



8. Are there any physical hazards within this living area?

2. Do all of the smoke detectors work, or does the system work?

☐

- 1 Yes
- 2 No

- 1 Yes
- 2 No

If yes, please explain:

---

---

---

3. Are all of the fire extinguishers properly charged?

- 1 Yes
- 2 No

4. Was there a fire drill in the past 60 days?

- 1 Yes
- 2 No
- 9 NA (minimal supervision)

5. Was there a fire drill in the 60 days before that?

- 1 Yes
- 2 No
- 9 NA (minimal supervision)

6. Is this person's living area reasonably clean?

- 1 Yes
- 2 No

If no, please explain:

---

---

---

7. Are there any excessively unpleasant odors in this living area?

- 1 Yes
- 2 No

If yes, please explain:

---

---

---

9. Does this individual have all prescribed adaptive equipment? (Base your judgment on the individual plan as well as any other documentation such as prescriptions, etc.)

1 Yes  
2 No

If No, please describe:

---

---

---

10. Are all living and program areas accessible to this individual?

1 Yes  
2 No

11. Does this individual have an Individualized Safety Plan?

1 Yes  
2 No

12. How safe is this neighborhood?

5 Extremely safe  
4 Safe  
3 Neither safe nor unsafe  
2 Unsafe  
1 Extremely unsafe

13. Is your neighborhood accessible in a way that meets your needs (e.g. ramps, curb cuts, audible traffic signals, etc.)?

3 Completely accessible  
2 Somewhat accessible  
1 Not accessible at all

## PLANNING

1. PLANNING DOCUMENT

Is there a planning document (IHP/IPP) that is current (within one year) for this person on site?

1 Yes  
2 No

## CASE MANAGEMENT/ SERVICE COORDINATION

1. Is there someone who acts on the person's behalf as the Individual Service Coordinator/Case Manager who provides service coordination for the individual; advocates on his/her behalf; provides networking and monitors the provision of support for this individual?

1 Yes  
2 No

## DIGNITY

1. Does the individual have personal possessions (e.g. tv, stereo, pictures, furniture, bicycle, knick knacks)?

1 Yes  
2 No

If No, please explain:

---

---

2. Does this individual have sufficient personal storage space? (e.g. closet space and a chest of drawers)

☐

- 1 Yes  
2 No

If No, please explain:

---

---

3. Does this individual have an adequate wardrobe, in both repair and fit?

☐

- 1 Yes  
2 No

If No, please explain:

---

---

4. Is the person dressed appropriately?

☐

- 1 Yes  
2 No

If No, please explain:

---

---



5. Is the person clean and groomed appropriately?

☐

- 1 Yes  
2 No

If No, please explain:

---

---

6. Is this person treated with respect?

☐

- 1 Yes  
2 No

If No, please explain:

---

---

### SELF DETERMINATION

1. What degree of freedom does this person have to make important decisions by him/herself which influence him/her everyday life?  
(Please circle your response below)

1                      2                      3                      4                      5

About the same  
degree of freedom  
as you and I

Some degree of  
freedom over  
everyday life

No degree  
of freedom

Tossebro, Jan (1995). Impact of Size Revisited: Relation of Number of Residents to Self-Determination and Deprivatization. *American Journal on Mental Retardation*, 1995, 100, 59-67.

## ADAPTIVE BEHAVIOR

- GIVE CREDIT ONLY FOR WHAT THE PERSON DOES DO, NOT FOR WHAT THE PERSON "CAN" DO OR "COULD" DO OR "MIGHT BE ABLE TO" DO. WE WANT NO SPECULATION - ONLY OBSERVED, ACTUAL BEHAVIORS.
- IF THE BEHAVIOR IS PERFORMED WITH VERBAL PROMPTS, GIVE CREDIT (UNLESS OTHERWISE NOTED IN THE ITEM). DO NOT GIVE CREDIT FOR BEHAVIORS PERFORMED WITH PHYSICAL GUIDANCE (UNLESS OTHERWISE NOTED IN THE ITEM).
- GIVE CREDIT FOR A BEHAVIOR IF IT IS PERFORMED AT LEAST 75% (THREE FOURTHS) OF THE TIME.
- ON ANY ITEM, A ZERO CAN BE ENTERED IF THE ITEM IS NOT APPLICABLE, OR IF THE PERSON IS TOO YOUNG, UNABLE, OR HAS NO OPPORTUNITY TO DISPLAY THE BEHAVIOR.
- ON ITEMS LIKE #1, CHECK ALL THAT APPLY, ADD UP THE NUMBER OF CHECKS, AND ENTER THAT NUMBER IN THE BOX.

1. WALKING AND RUNNING (Check ALL that apply. With cane, crutches, brace, or walker, if used.)

- ☐ a Walks alone
  - ☐ b Walks up and down stairs alone
  - ☐ c Walks down stairs by alternating feet
  - ☐ d Runs without falling often
  - ☐ e Hops, skips or jumps
- (NONE OF THE ABOVE: ENTER 0)

2. BODY BALANCE

- 5 Stands on "tiptoe" for ten seconds if asked
- 4 Stands on one foot for two seconds if asked
- 3 Stands without support
- 2 Stands with support
- 1 Sits without support
- 0 Can do none of the above

3. USE OF TABLE UTENSILS

- 6 Uses knife and fork correctly and neatly

- 5 Uses table knife for cutting or spreading
- 4 Feeds self with spoon and fork - neatly
- 3 Feeds self with spoon and fork - considerable spilling
- 2 Feeds self with spoon - neatly
- 1 Feeds self with spoon - considerable spilling
- 0 Feeds self with fingers or must be fed

4. EATING IN PUBLIC (Visual aids are acceptable)

☐

- 3 Orders complete meals in restaurants
- 2 Orders simple meals like hamburgers or hot dogs
- 1 Orders soft drinks at soda fountain or canteen
- 0 Does not order food at public eating places

5. DRINKING

☐

- 3 Drinks without spilling, holds glass in one hand
- 2 Drinks from cup or glass unassisted - neatly
- 1 Drinks from cup or glass - considerable spilling
- 0 Does not drink from cup or glass

6. TOILETING

☐

- 4 Never has toilet accidents
- 3 Never has toilet accidents during the day
- 2 Occasionally has toilet accidents during the day
- 1 Frequently has toilet accidents during the day
- 0 Is not toilet trained at all

7. SELF-CARE AT TOILET (Check ALL that apply)

☐

- \_\_\_ a Lowers pants at the toilet without help
  - \_\_\_ b Sits on toilet seat without help
  - \_\_\_ c Uses toilet tissue appropriately
  - \_\_\_ d Flushes toilet after use
  - \_\_\_ e Puts on clothes without help
  - \_\_\_ f Washes hands without help
- (NONE OF THE ABOVE: ENTER 0)

8. WASHING HANDS AND FACE (Check ALL that apply)

☐

- \_\_\_ a Washes hands with soap
  - \_\_\_ b Washes face with soap
  - \_\_\_ c Washes hands and face with water
  - \_\_\_ d Dries hands and face
- (NONE OF THE ABOVE: ENTER 0)



9. BATHING

☐

- 6 Prepares and completes bathing unaided
- 5 Washes and dries self completely
- 4 Washes and dries reasonably well with prompting
- 3 Washes and dries self with help
- 2 Attempts to soap and wash self
- 1 Cooperates when being washed and dried by others
- 0 Makes no attempt to wash or dry self

10. CARE OF CLOTHING (Check ALL that apply)

☐

- ☐ a Cleans shoes when needed
- ☐ b Puts clothes in drawer or chest neatly
- ☐ c Puts soiled clothes in proper place for laundering/washing, without being reminded
- ☐ d Hangs up clothes without being reminded

(NONE OF THE ABOVE: ENTER 0)

11. DRESSING

☐

- 5 Completely dresses self
- 4 Completely dresses self with verbal prompting only
- 3 Dresses self by pulling or putting on all clothes with verbal prompting and by fastening (zipping, buttoning, snapping) them with help
- 2 Dresses self with help in pulling or putting on most clothes and fastening them
- 1 Cooperates when dressed, e.g., by extending arms or legs
- 0 Must be dressed completely

12. SHOES (Check ALL that apply)

☐

- ☐ a Puts on shoes correctly without assistance
- ☐ b Ties shoe laces without assistance (Velcro does not count)
- ☐ c Unties shoe laces without assistance
- ☐ d Removes shoes without assistance

(NONE OF THE ABOVE: ENTER 0)

13. SENSE OF DIRECTION

☐

- 3 Goes several blocks from grounds, or from home, without getting lost
- 2 Goes around grounds or a couple of blocks from home without getting lost
- 1 Goes around cottage, ward, yard, or home without getting lost
- 0 Demonstrates no sense of direction

14. MONEY HANDLING

☐

- 4 Uses money with little or no assistance (e.g., assistance with budgeting is OK)
- 3 Uses money with minor assistance (e.g., checking for correct change, etc.)
- 2 Uses money with some assistance (e.g., being told the correct bills or coins)
- 1 Uses money with complete assistance of staff
- 0 Does not use money

15. PURCHASING

☐

- 5 Chooses and buys all own clothing without help
- 4 Chooses and buys some clothing without help
- 3 Makes minor purchases without help (e.g., snacks, drinks)
- 2 Does some shopping with slight supervision
- 1 Does some shopping with close supervision
- 0 Does no shopping

16. WRITING

☐

- 5 Writes complete lists, memos, or letters
- 4 Writes short sentences
- 3 Writes or prints more than ten words without copying or tracing
- 2 Writes or prints own name or other words without copying or tracing
- 1 Traces or copies own name or other words
- 0 Does not write, print, copy, or trace any words

17. PREVERBAL EXPRESSION (Check ALL that apply)

☐

- \_\_\_ a Is able to say (sign) at least a few words  
(If so, enter a "6" in the circle)
  - \_\_\_ b Nods head or smiles to express happiness
  - \_\_\_ c Indicates hunger
  - \_\_\_ d Indicates wants by pointing or vocal noises
  - \_\_\_ e Expresses pleasure or anger by vocal noises
  - \_\_\_ f Chuckles or laughs when happy
- (NONE OF THE ABOVE: ENTER 0)

18. SENTENCES

☐

- 3 Sometimes uses complex sentences containing "because," "but," etc.
- 2 Asks questions using words such as "why," "how," "what," etc.
- 1 Speaks in simple sentences
- 0 Is non-verbal or nearly non-verbal

19. READING

- 5 Reads books or other materials suitable for children 9 years old or older
- 4 Reads books or other materials suitable for children 7 years old
- 3 Reads simple stories or comics suitable for kindergarten or 1st grade level
- 2 Recognizes 10 or more words
- 1 Recognizes various signs, such as "EXIT" or "STOP" or "WOMEN" or "MEN" or street signs.
- 0 Recognizes no words or signs.

20. COMPLEX INSTRUCTIONS (Check ALL that apply)

- \_\_\_ a Understands instructions containing prepositions, e.g., "on," "in," "behind"
  - \_\_\_ b Understands instructions referring to the order in which things must be done, e.g., "first do this, and afterward, do that."
  - \_\_\_ c Understands instructions requiring a decision, e.g., "If there's any ham, make
- (NONE OF THE ABOVE: ENTER 0)

21. NUMBERS

- 5 Does simple addition and/or subtraction
- 4 Counts 10 or more objects
- 3 Mechanically counts aloud from 1 to 10
- 2 Counts 2 objects between saying "one, two"
- 1 Discriminates between "one" and "many"
- 0 Has no understanding of numbers

22. TIME (Check ALL that apply)

- \_\_\_ a Tells time by clock or watch correctly
  - \_\_\_ b Understands time intervals, e.g., there is 1 hour between 3:30 and 4:30
  - \_\_\_ c Understands time equivalents, e.g., "9:15" is the same as "quarter past nine"
  - \_\_\_ d Associates time on clock with various actions and events, e.g., 6:00 means dinner time
- (NONE OF THE ABOVE: ENTER 0)



## 28. ATTENTION

### 23. ROOM CLEANING

- 2 Cleans room well, e.g., sweeping, vacuuming, tidying
- 1 Cleans room but not thoroughly
- 0 Does not clean room at all

### 24. FOOD PREPARATION

- 3 Prepares an adequate complete meal (may use canned or frozen foods)
- 2 Mixes and cooks simple foods, e.g., fries eggs, makes pancakes, cooks TV dinners, can of soup
- 1 Prepares simple foods requiring no mixing or cooking, e.g., sandwiches, cold cereal, etc.
- 0 Does not prepare food at all

### 25. TABLE CLEARING

- 2 Clears table of breakable dishes and glassware
- 1 Clears table of unbreakable dishes and silverware
- 0 Does not clear table at all

### 26. JOB COMPLEXITY

- 2 Competitive employment or goes to workshop
- 1 In pre-vocational training, in school, or retired
- 0 Performs no work

### 27. INITIATIVE

- 3 Initiates most of own activities
- 2 Initiates some of own activities
- 1 Will engage in activities only if assigned or directed
- 0 Will not engage in assigned activities

- 4 Will pay attention to purposeful activities for more than 20 minutes
- 3 Will pay attention to purposeful activities for about 15 minutes
- 2 Will pay attention to purposeful activities for about 10 minutes
- 1 Will pay attention to
- 0 Will not pay attention to purposeful activities for as long as 5 minutes

### 29. PERSONAL BELONGINGS

- 3 Very dependable, always takes care of belongings
- 2 Usually dependable, usually takes care of belongings
- 1 Unreliable, seldom takes care of belongings
- 0 Not responsible at all, does not take care of belongings

### 30. AWARENESS OF OTHERS (Check ALL that apply)

- ☐ a Recognizes own family
  - ☐ b Recognizes people other than family (If "b" is checked, also check "a")
  - ☐ c Has information about others, e.g., relation to self, job, address, name
  - ☐ d Knows the names of people close to him/her, e.g., in neighborhood, at home or day program
  - ☐ e Knows the names of people not regularly encountered
- (NONE OF THE ABOVE: ENTER 0)

### 31. INTERACTION WITH OTHERS

- 3 Interacts with others for more than 5 minutes
- 2 Interacts with others for up to 5 minutes
- 1 Interacts with others in limited ways, e.g., eye contact, handshakes, responsive to touch
- 0 Does not interact with others in a socially acceptable manner

### 32. PARTICIPATION IN GROUP ACTIVITIES





- 3 Initiates group activities at least some of the time (leader and/or organizer)
- 2 Participates in group activities spontaneously and eagerly (active participant)
- 1 Participates in group activities if encouraged to do so (passive participant)
- 0 Does not participate in group activities (unless physically guided)

### CHALLENGING BEHAVIOR IN THE PAST 4 WEEKS:

## FREQUENCY

- |   |  |
|---|--|
| 2 | Not observed in the past 4 weeks       |
| 1 | 5 times/week or less in past 4 weeks   |
| 0 | More than 5 times/week in past 4 weeks |

11

- ## 12. Socially unacceptable sexual behavior

13. Listless, sluggish, inactive, unresponsive to activities

- 14. Screams, yells, or cries inappropriately**

15. Repeats a word or phrase over and over

16. Threatens violence to self

1. Threatens or does physical violence to others

- ## 2. Damages own or others' property

3. Disrupts others' activities (intentionally)

4. Uses profane or hostile language

5. Is rebellious, e.g., ignores regulations, resists following instructions

6. Runs away or attempts to run away (intentionally)

7. Is untrustworthy, e.g., takes others' property, lies, or cheats

8. Displays stereotyped behavior, e.g., rocks body, hands constantly moving in repetitive pattern

9. Removes or tears off own clothing inappropriately

10. Injures self

11. Is hyperactive, e.g., will not sit still for any length of time

SEVERITY

- 3 No problem  
 2 Minor problem  
 1 Major problem  
 0 Extremely urgent problem, completely or nearly intolerable

☐

17. Threatens or does physical violence to others

☐

18. Damages own or others' property

☐

19. Disrupts others' activities (intentionally)

☐

20. Uses profane or hostile language

☐

21. Is rebellious, e.g., ignores regulations, resists following instructions

☐

22. Runs away or attempts to run away (intentionally)

☐

23. Is untrustworthy, e.g., takes others' property, lies, or cheats

☐

24. Displays stereotyped behavior, e.g., rocks body, hands constantly moving in repetitive pattern

☐

25. Removes or tears off own clothing inappropriately

☐

26. Injures self

☐

27. Is hyperactive, e.g., will not sit still for any length of time

☐

28. Socially unacceptable sexual behavior

☐

29. Listless, sluggish, inactive, unresponsive to activities

☐

30. Screams, yells, or cries inappropriately

☐

31. Repeats a word or phrase over and over

☐

32. Threatens violence to self

33. Did this person display any serious challenging behavior that did not happen in the past four weeks that is of serious concern to staff? Describe:

34. Does this person have a severe reputation? If yes, what is it and what impact does it have on this person's life? Describe:



**COMMUNITY INTEGRATION / INCLUSION  
SOCIAL PRESENCE IN THE PAST WEEK (Copyright CFA 1987)**

We define SOCIAL PRESENCE as the frequency of "CONTACT" with PEOPLE WITHOUT DISABILITIES WHO DO NOT LIVE WITH, AND WHO ARE NOT PAID TO INTERACT WITH, this individual. People who are paid to interact with this individual include residential and day program staff, case managers, doctors, physical and occupational therapists, etc.

"CONTACT" is defined as:

An event of more than 5 minutes in which the individual:

- interacts with, or
- is seen by, or
- is in the presence of people without disabilities.

For each category below, enter the number of times "CONTACT" has occurred for this person in the **PAST WEEK**. Limit the number of contacts to 5 per day or 35 per week in any category. If the person is in supported or competitive employment, score a maximum of 5 contacts for each day at work. Riding the bus one way equals one contact.

SETTING TYPE	GROUP SIZE (NUMBER OF PEOPLE WITH DISABILITIES WHO WERE PRESENT)			HOW MANY OF THESE CONTACTS INVOLVED COMMUNICATION
	1	2 to 5	6 or MORE	
IN OWN OR OTHER PERSON'S HOME, OR IN OWN OR OTHER PERSON'S NEIGHBORHOOD	<u>1.</u>	<u>2.</u>	<u>3.</u>	<u>4.</u>
RECREATIONAL	<u>5.</u>	<u>6.</u>	<u>7.</u>	<u>8.</u>
COMMERCIAL	<u>9.</u>	<u>10.</u>	<u>11.</u>	<u>12.</u>
DAY PROGRAM/JOBS	<u>13.</u>	<u>14.</u>	<u>15.</u>	<u>16.</u>
DURING TRANSPORTATION	<u>17.</u>	<u>18.</u>	<u>19.</u>	<u>20.</u>

21.

☐

Check here if there has not been any contact with people without disabilities in the past week.

**HARRIS SCALE OF INTEGRATED ACTIVITIES**

22. About how often did this person do each of the following in the past year:

- ☐ a. Visit with close friends, relatives or neighbors
- ☐ b. Visit a supermarket or food store
- ☐ c. Go to a restaurant
- ☐ d. Go to church or synagogue
- ☐ e. Go to a shopping center, mall or other retail store to shop
- ☐ f. Go to bars, taverns, etc.

\_\_\_ g. Go to the bank

- 1 = More than twice a week
- 2 = Twice a week
- 3 = Once a week
- 4 = 2-3 times a month
- 5 = Once a month
- 6 = Less than once a month
- 7 = Never
- 9 = Not sure or refused

**CONSUMER SATISFACTION  
INTERVIEW WITH PERSON (Copyright CFA 1986)**

These questions should be answered by the consumer, and if appropriate and feasible, should be answered in private.

Ask the person if he/she is willing to talk to you. If not, do not proceed; enter all 0's.

A zero (0) should be used when an item is not applicable, or for which the person is too young or unable to respond, or if no answer is given.

Ask the person if it is OK to tell others what you are telling me. If not, do not record verbatim responses.

1. DO YOU LIKE THE FOOD HERE?

☐

- 3 Yes, like food
- 2 In between, sort of, unsure, etc.
- 1 No, do not like food
- 0 Did not answer

2. DO YOU LIKE LIVING HERE?

☐

- 3 Yes, like living here
- 2 In between, sort of, unsure, etc.
- 1 No, do not like living here
- 0 Did not answer

3. PLEASE LET ME CHECK - DID YOU SAY THE FOOD HERE IS BAD OR GOOD?

☐

- 3 Good
- 2 In between, sort of, unsure, etc.
- 1 Bad
- 0 Did not answer

4. DO YOU LIKE THE PEOPLE WHO WORK HERE?

☐

- 3 Yes
- 2 Somewhat, most, not all, etc.
- 1 No
- 0 Did not answer

5. DO YOU HAVE ENOUGH CLOTHES TO WEAR?

☐

- 3 Yes, enough clothes
- 2 In between, sort of, unsure, etc.
- 1 No, not enough clothes
- 0 Did not answer

6. DO YOU HAVE ANY REAL GOOD FRIENDS?

☐

- 4 Yes, more than one
- 3 Yes, one
- 2 In between, sort of, unsure, etc.
- 1 No, no real good friends
- 0 Did not answer

7. ARE PEOPLE WHO WORK HERE MEAN OR NICE?

☐

- 3 Nice
- 2 In between, unsure, etc.
- 1 Mean
- 0 Did not answer

8. DO YOU LIKE WHAT YOU DO DURING THE DAY? (JOB, DAY PROGRAM, ETC.)

☐

- 3 Yes
- 2 In between, sort of, unsure, etc.
- 1 No
- 0 Did not answer

9. DO YOU MAKE ANY MONEY?

☐

- 3 Yes
- 2 Unsure, etc.
- 1 No
- 0 Did not answer

10. IS IT ENOUGH TO MEET YOUR NEEDS?

☐

- 3 Yes
- 2 Unsure, etc.
- 1 No
- 0 Did not answer

11. DO YOU KNOW WHAT MEDICATION YOU TAKE?



☐

- 3 Yes
- 2 Unsure, etc.
- 1 No
- 0 Did not answer

12. DOES THE MEDICATION YOU TAKE HELP YOU?

☐

- 3 Yes
- 2 Unsure, etc.
- 1 No
- 0 Did not answer

13. DO YOU HAVE A CHOICE ABOUT WHAT MEDICATION YOU TAKE?

☐

- 3 Yes
- 2 Unsure, etc.
- 1 No
- 0 Did not answer

14. DO YOU HAVE ENOUGH PRIVACY HERE?

☐

- 3 Yes
- 2 Unsure, etc.
- 1 No
- 0 Did not answer

15. DO YOU KNOW WHO YOUR CASE MANAGER IS?

☐

- 3 Yes
- 2 Unsure, etc.
- 1 No
- 0 Did not answer

16. DO YOU SEE YOUR CASE MANAGER AT LEAST ONCE EVERY MONTH?

☐

- 3 Yes
- 2 Unsure, etc.
- 1 No
- 0 Did not answer

17. DID YOU HELP DEVELOP YOUR PLAN?

☐

- 3 Yes
- 2 Unsure, etc.
- 1 No
- 0 Did not answer

18. DO YOU AGREE WITH EVERYTHING IN YOUR PLAN?

☐

- 3 Yes
- 2 Unsure, etc.
- 1 No
- 0 Did not answer

19. IS THERE ANYTHING ELSE THAT YOU WOULD LIKE TO TELL ME?  
(Record response word for word. Editor will code)

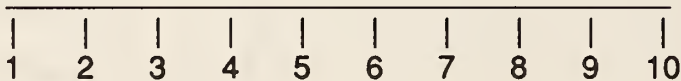
21. IF ALL ANSWERS TO CONSUMER INTERVIEW WERE 0, WHY?

☐

- 2 Did not choose to answer questions
- 1 Not able to answer questions
- 0 Other \_\_\_\_\_

### Reviewer's Impressions Specific to this Person

1. On a scale of 1-10, how good is this person's life?



- 1 = I can't imagine anything worse.
- 3 = Poor
- 5 = Mediocre
- 7 = Desirable
- 10 = I'd switch lives in a minute.

## RELATIONSHIPS/SOCIAL CONNECTIONS

### INSTRUCTIONS

Information is gathered during the interview with the person or their representative. The person is asked to identify people who are important to them in the following categories. A person can only be listed in one category. The reviewer should seek to determine 1) the frequency of contact during the last year. Complete the analysis at the end of the form using the information gathered from the interview. This tool was adapted from the Social Network Analysis Form developed by Horner, Reed, Ritchie, Stoner and Twain (1986).

INDIVIDUAL'S IN THE PERSON'S SOCIAL NETWORK		How often have you seen or done things with this person in the last year?
Family Members		
Room Mates		
Co-Workers		
School Mates		
Paid Staff to provide support or services		
Friends		
Neighbors/ Others		
<b>ANALYSIS OF PERSON'S SOCIAL NETWORK - EDITOR ONLY</b>		
Total Network Size	Total less Paid People	Family
Co-Workers	Friends	Neighbors



## INDIVIDUALISM / SELF DETERMINATION

1. Does this person get up when s/he chooses?

☐

- 2 Yes, completely flexible, determined by individual's needs and desires.
- 1 Sometimes, on weekends and holidays, determined by individual's needs and desires.
- 0 No, Person adheres to established household routine.
- 9 NA

2. Does this person choose when s/he eats her meals?

☐

- 2 Yes, completely flexible, determined by individual's needs and desires.
- 1 Sometimes, on weekends and holidays, determined by individual's needs and desires.
- 0 No, Person adheres to established household routine.
- 9 NA

3. Does this person have a choice about when s/he goes to bed?

- 2 Yes, completely flexible, determined by individual's needs and desires.
- 1 Sometimes, on weekends and holidays, determined by individual's needs and desires.
- 0 No, Person adheres to established household routine.
- 9 NA

4. Is this person involved in planning his/her meals?

- 3 Individual has the major role in the decision
- 2 Staff encourage the person's participation to the maximum extent possible
- 1 Staff encourage the individual's participation somewhat (more could be done)
- 0 Staff do this with little or no input from individual
- 9 NA (No, individual not capable of any input)

5. Does this person shop for groceries?

- 3 Individual has the major role in the decision
- 2 Staff encourage the person's participation to the maximum extent possible
- 1 Staff encourage the individual's participation somewhat (more could be done)
- 0 Staff do this with little or no input from individual
- 9 NA (No, individual not capable of any input)

6. Does this person shop for her/his own clothing and personal articles?

- 3 Individual has the major role in the decision
- 2 Staff encourage the person's participation to the maximum extent possible

- 1 Staff encourage the individual's participation somewhat (more could be done)
- 0 Staff do this with little or no input from individual
- 9 NA (No, individual not capable of any input)

7. Does this person do her/his own banking?

- 3 Individual has the major role in the decision
- 2 Staff encourage the person's participation to the maximum extent possible
- 1 Staff encourage the individual's participation somewhat (more could be done)
- 0 Staff do this with little or no input from individual
- 9 NA (No, individual not capable of any input)

8. Is this individual a participant in deciding how household chores are allocated ?

- 3 Individual has the major role in the decision
- 2 Staff encourage the person's participation to the maximum extent possible
- 1 Staff encourage the individual's participation somewhat (more could be done)
- 0 Staff do this with little or no input from individuals
- 9 NA (No, individual not capable of any input)

9. Does this person participate in organizing social events, visits, parties?

- 3 Individual has the major role in the decision
- 2 Staff encourage the person's participation to the maximum /extent possible
- 1 Staff encourage the individual's participation somewhat (more could be done)
- 0 Staff do this with little or no input from individual
- 9 NA (No, individual not capable of any input)

10. Did the individual choose the place where he/she lives?

- 1 Yes, the individual chose the place unassisted
- 2 Yes, with assistance from personal unpaid friend
- 3 Yes, with assistance from family member
- 4 Yes, with assistance from a legal guardian
- 5 Yes, with assistance from agency/school staff member
- 6 No, personal unpaid friend
- 7 No, family member
- 8 No, legal guardian
- 9 No, agency/school staff member
- 0 Other, not applicable, or unknown (including court)

11. Did the individual choose her/his attendant and/or residential support staff?

- 1 Yes, the individual chose unassisted
- 2 Yes, with assistance from personal unpaid friend
- 3 Yes, with assistance from family member
- 4 Yes, with assistance from a legal guardian
- 5 Yes, with assistance from agency/school staff member
- 6 No, personal unpaid friend
- 7 No, family member
- 8 No, legal guardian
- 9 No, agency/school staff member
- 0 Other, not applicable, or unknown

12. Did the individual choose his/her roommates/housemates?

- 1 Yes, the individual chose unassisted
- 2 Yes, with assistance from personal unpaid friend
- 3 Yes, with assistance from family member
- 4 Yes, with assistance from a legal guardian
- 5 Yes, with assistance from agency/school staff member
- 6 No, personal unpaid friend
- 7 No, family member
- 8 No, legal guardian
- 9 No, agency/school staff member
- 0 Other, not applicable, or unknown

13. Did the individual choose his/her job or what the individual does during the week?

- 1 Yes, the individual chose unassisted
- 2 Yes, with assistance from personal unpaid friend
- 3 Yes, with assistance from family member
- 4 Yes, with assistance from a legal guardian
- 5 Yes, with assistance from agency/school staff member
- 6 No, personal unpaid friend
- 7 No, family member
- 8 No, legal guardian



14. Does the individual usually choose what he/she does on the weekends and evenings?

- 1 Yes, the individual chose unassisted
- 2 Yes, with assistance from personal unpaid friend
- 3 Yes, with assistance from family member
- 4 Yes, with assistance from a legal guardian
- 5 Yes, with assistance from agency/school staff member
- 6 No, personal unpaid friend
- 7 No, family member
- 8 No, legal guardian
- 9 No, agency/school staff member
- 0 Other, not applicable, or unknown

15. Does the individual give his/her own consent for medical care?

- 1 Yes, the individual chose unassisted
- 2 Yes, with assistance from personal unpaid friend
- 3 Yes, with assistance from family member
- 4 Yes, with assistance from a legal guardian
- 5 Yes, with assistance from agency/school staff member
- 6 No, personal unpaid friend
- 7 No, family member
- 8 No, legal guardian
- 9 No, agency/school staff member
- 0 Other, not applicable, or unknown

16. Does the individual determine what clothes he/she wears?

- 1 Yes, the individual chose unassisted
- 2 Yes, with assistance from personal unpaid friend
- 3 Yes, with assistance from family member
- 4 Yes, with assistance from a legal guardian
- 5 Yes, with assistance from agency/school staff member
- 6 No, personal unpaid friend
- 7 No, family member
- 8 No, legal guardian
- 9 No, agency/school staff member
- 0 Other, not applicable, or unknown

17. Does the individual usually choose her/his friends and acquaintances?

- 1 Yes, the individual chose unassisted
- 2 Yes, with assistance from personal unpaid friend
- 3 Yes, with assistance from family member
- 4 Yes, with assistance from a legal guardian
- 5 Yes, with assistance from agency/school staff member
- 6 No, personal unpaid friend
- 7 No, family member
- 8 No, legal guardian
- 9 No, agency/school staff member
- 0 Other, not applicable, or unknown

18. Does the individual usually decide how her/his personal space (home, apartment, bedroom, etc.) is decorated?

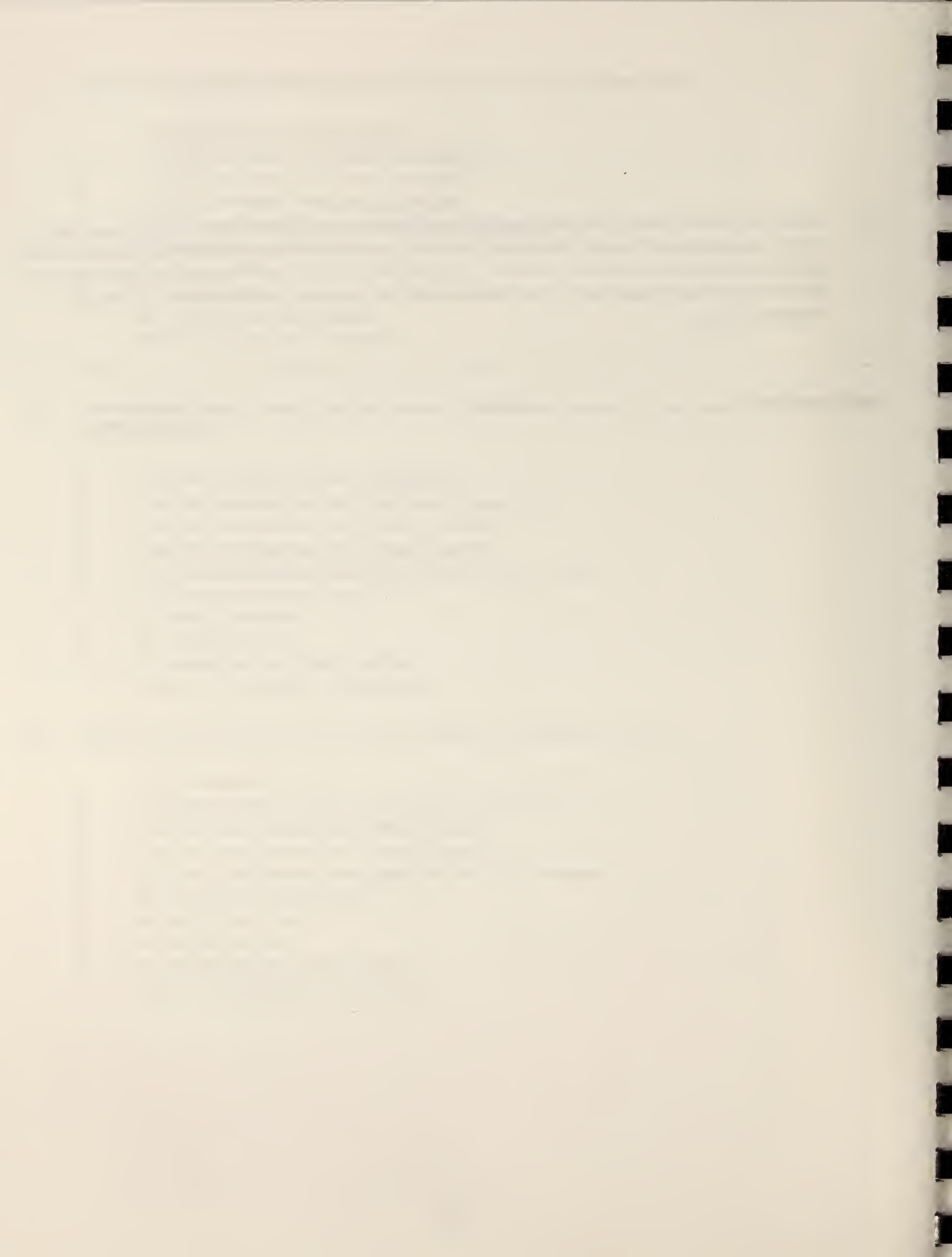
- 1 Yes, the individual chose unassisted
- 2 Yes, with assistance from personal unpaid friend
- 3 Yes, with assistance from family member
- 4 Yes, with assistance from a legal guardian
- 5 Yes, with assistance from agency/school staff member
- 6 No, personal unpaid friend
- 7 No, family member
- 8 No, legal guardian
- 9 No, agency/school staff member
- 0 Other, not applicable, or unknown

19. Does the individual go to the bank and deposit and withdraw money?

- 1 Yes, unassisted
- 2 Yes, with assistance from personal unpaid friend
- 3 Yes, with assistance from family member
- 4 Yes, with assistance from a legal guardian
- 5 Yes, with assistance from agency/school staff member
- 6 No, personal unpaid friend
- 7 No, family member
- 8 No, legal guardian
- 9 No, agency/school staff member
- 0 Other, not applicable, or unknown

- 1 2 3 4 5
- Totally independent Neutral Not at all independent





## HEALTH AND SAFETY ISSUES INSTRUMENT





1 _____ Sequence #	2 _____ Editor	3 _____ SR	4 _____ Site Code
FOR OFFICE USE ONLY			

# EVALUATION OF ICFs/MR

## HEALTH AND SAFETY ISSUES

Developed by:  
 Temple University  
 Institute on Disabilities/UAP  
 September 22, 1995

*Please Print*

Person's Social Security # \_\_\_\_\_

Person's Name \_\_\_\_\_

Last	First	M.I.
------	-------	------

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\_\_\_\_\_ Residential Provider

\_\_\_\_\_ Complete Site Mailing Address

City, Town	State	Zip Code
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\_\_\_\_\_ Primary Respondent Name

\_\_\_\_\_ (      ) Telephone

---

\_\_\_\_\_ Name of Data Collector

## DEMOGRAPHICS

### 1. TODAY'S DATE

\_\_\_\_/\_\_\_\_/\_\_\_\_  
Month Year

### 2. PERSON'S DATE OF BIRTH

\_\_\_\_/\_\_\_\_/\_\_\_\_  
Month Day Year

### 3. RESIDENTIAL PLACEMENT TYPE

☐

- 1 Public Institution (Not ICF/MR)
- 2 ICF/MR, 16 beds or more
- 3 ICF/MR, 4 to 15 beds
- 4 Community Living Arrangement, group home or apartment (30 hours or more of staff time per week)
- 5 Community Living Arrangement, group home or apartment (Less than 30 hours of staff time per week)
- 6 Supported Living (30 hours or more of staff time per week)
- 7 Supported Living (Less than 30 hours of staff time per week)
- 8 Home and Community Based Waiver Services (in-home)
- 9 Foster Family, Family Living Program
- 10 With Family or in own Home
- 11 Nursing Home
- 12 Other (Describe) \_\_\_\_\_

### 4. LEVEL OF RETARDATION (Please seek documentation)

☐

- 5 Profoundly retarded
- 4 Severely retarded
- 3 Moderately retarded
- 2 Mildly retarded
- 1 Not mentally retarded

5. OTHER DISABILITIES  
Seek documentation. Enter code in box.  
Leave none blank.

- 1 Yes  
0 No  
9 Don't know

☐

Blind

☐

Mental Disorder

☐

Autism

☐

Cerebral Palsy

☐

Epilepsy, Controlled

☐

Epilepsy, Uncontrolled

☐

Non-Ambulatory, Mobile

☐

Non-Ambulatory, Non-Mobile

☐

Speech/Language Impairment

☐

Hard of Hearing

☐

Deaf

☐

Visual Impairment

Other Health Impairment (specify):

---

---

---



6. SEX

☐

- 1 Male
- 2 Female

7. RACE

☐

- 1 White
- 2 African-American
- 3 Latino
- 4 Asian
- 5 Other

**HEALTH AND SAFETY**

**MEDICATION:**

1. How many medications does this individual take on a daily basis? Count each medication that is given to this person daily and that is prescribed. Do not count vitamins or topical ointments. Enter the exact number.

\_\_\_\_\_

2. Is this individual receiving any medication for the purpose of behavior change?

☐

- 1 Yes
- 2 No

3. If this individual is receiving medication for the purpose of behavior change, has the prescribing physician certified the continuing medication within the past 90 days?

☐

- 1 Yes
- 2 No
- 9 NA - no medication for behavior control

## MEDICAL NEEDS:

1. In general, how urgent is this person's need for medical care?

☐

- 3 Generally has no serious medical needs  
2 Needs visiting nurse and/or regular visits to the doctor  
1 Has life-threatening condition that requires very rapid access to medical care  
0 Would not survive without 24-hour medical care

2. How many times has this person seen each of the following doctors in the past year?

- \_\_\_\_\_ a. General Practitioner/Internist  
\_\_\_\_\_ b. Obstetrics/Gynecologist  
\_\_\_\_\_ c. Psychiatrist  
\_\_\_\_\_ d. Dentist  
\_\_\_\_\_ e. Podiatrist  
\_\_\_\_\_ f. All others

3. Has there been a problem getting medical care during the past year?

☐

- 2 No problem  
1 Minor or occasional problem(s)  
0 Major or frequent problem(s)

Describe the problem:

---

---

---

4. Has there been a problem getting dental care during the past year?

☐

- 2 No problem  
1 Minor or occasional problem(s)  
0 Major or frequent problem(s)

Describe the problem:

---

---

---

5. Has there been a problem getting mental health care during the past year?

☐

- 2 No problem  
1 Minor or occasional problem(s)  
0 Major or frequent problem(s)

Describe the problem:

---

---

---

6. Does this person have an Individual Health Care Plan?

☐

- 1 Yes  
2 No

- \_\_\_\_ f. Fire requiring fire department  
\_\_\_\_ g. Emergency program relocation  
\_\_\_\_ h. Alleged misuse of client funds or property  
\_\_\_\_ i. Outbreak of communicable disease  
\_\_\_\_ j. Alleged violation of client rights  
\_\_\_\_ k. Other (please specify)

## UNUSUAL INCIDENT REPORTS

1. Have there been any unusual incidents involving this individual in the past 6 months that you have reviewed?

☐

- 1 Yes  
2 No

2. If yes, how many? (Enter exact number)

---

3. For the unusual incidents you identified, please indicate how many of each type were reported.

- \_\_\_\_ a. Injury/illness requiring hospital admission  
\_\_\_\_ b. Serious illness requiring doctor  
\_\_\_\_ c. Medication error  
\_\_\_\_ d. Suicide attempt  
\_\_\_\_ e. Unauthorized absence - immediate jeopardy or more than 24 hours



4. For the unusual incidents you identified, please indicate how many of each type were reported .

a. Rape (alleged) \_\_\_\_\_Victim

Rape (alleged) \_\_\_\_\_Perpetrator

b. Assault (alleged) \_\_\_\_\_Victim

Assault (alleged) \_\_\_\_\_Perpetrator

c. Abuse (alleged) \_\_\_\_\_Victim

Abuse (alleged) \_\_\_\_\_Perpetrator

d. Serious behavior incident: police involvement  
with a client specific incident

\_\_\_\_\_Victim

\_\_\_\_\_Perpetrator

e. Serious behavior incident: emergency  
restraint

\_\_\_\_\_Victim

\_\_\_\_\_Perpetrator

5. Are there any instances of abuse, neglect, or mistreatment that have gone untreated?  
(Please look at 1 month's daily logs).

☐

1 Yes

2 No

If yes, please describe:

\_\_\_\_\_

\_\_\_\_\_

## BEHAVIOR PLAN

1. Does this person have a formal behavior plan?

☐

1 Yes

2 No

2. Is there any evidence of use of physical restraints?

☐

- 1 Yes  
2 No

If yes, when did they occur?

---

---

---

3. If the answer to question 2 is yes, are the use of restraints part of a program plan?

☐

- 1 Yes  
2 No  
9 NA

4. Is there any evidence of use of Time-Out Rooms?

☐

- 1 Yes  
2 No

If yes, when did the use occur?

---

---

---

5. If the answer to question 4 is yes, is the use of the Time-Out Room part of a program plan?

☐

- 1 Yes  
2 No  
9 NA

6. Is there any evidence of the use of painful and/or noxious stimuli?

☐

- 1 Yes  
2 No

If yes, when did the use occur?

---

7. If the answer to question 6 was yes, is the use of painful and/or noxious stimuli part of a program plan?

☐

- 1 Yes  
2 No  
9 NA

8. Are there any unusual incidents that have not been reported? (Look for documentation)

☐

- 1 Yes  
2 No

Describe the incident:

---

---

---

## SAFETY

1. Are there adequate number of smoke detectors in this house/apartment /living area (one per floor including attic and basement)?

☐

- 1 Yes  
2 No

2. Do all of the smoke detectors work, or does the system work?

☐

- 1 Yes  
2 No

3. Are all of the fire extinguishers properly charged?

☐

- 1 Yes  
2 No

4. Was there a fire drill in the past 60 days?

☐

- 1 Yes
- 2 No
- 9 NA (minimal supervision)

5. Was there a fire drill in the 60 days before that?

☐

- 1 Yes
- 2 No
- 9 NA (minimal supervision)

6. Is this person's living area reasonably clean?

☐

- 1 Yes
- 2 No

If no, please explain:

---

---

---

7. Are there any excessively unpleasant odors in this living area?

☐

- 1 Yes
- 2 No

If yes, please explain:

---

---

---

8. Are there any physical hazards within this living area?

☐

- 1 Yes
- 2 No

If yes, please explain:

---



9. Does this individual have all prescribed adaptive equipment? (Base your judgment on the individual plan as well as any other documentation such as prescriptions, etc.)

☐

- 1 Yes  
2 No

If No, please describe:

---

---

---

10. Are all living and program areas accessible to this individual?

☐

- 1 Yes  
2 No

11. Does this individual have an Individualized Safety Plan?

☐

- 1 Yes  
2 No

12. How safe is this neighborhood?

☐

- 5 Extremely safe  
4 Safe  
3 Neither safe nor unsafe  
2 Unsafe  
1 Extremely unsafe

13. Is your neighborhood accessible in a way that meets your needs (e.g. ramps, curb cuts, audible traffic signals, etc.)?

☐

- 3 Completely accessible  
2 Somewhat accessible  
1 Not accessible at all

## DEMOGRAPHICS

1. TODAY'S DATE

\_\_\_\_/\_\_\_\_/\_\_\_\_  
Month Year

2. PERSON'S DATE OF BIRTH

\_\_\_\_/\_\_\_\_/\_\_\_\_  
Month Day Year

3. RESIDENTIAL PLACEMENT TYPE

☐

- 1 Public Institution (Not ICF/MR)
- 2 ICF/MR, 16 beds or more
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- 4 Community Living Arrangement, group home or apartment (30 hours or more of staff time per week)
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- 8 Home and Community Based Waiver Services (in-home)
- 9 Foster Family, Family Living Program
- 10 With Family or in own Home
- 11 Nursing Home
- 12 Other (Describe) \_\_\_\_\_

4. LEVEL OF RETARDATION  
(Please seek documentation)

☐

- 5 Profoundly retarded
- 4 Severely retarded
- 3 Moderately retarded
- 2 Mildly retarded
- 1 Not mentally retarded





## **APPENDIX C**

- 1 STATE BY STATE ANALYSES OF PSYCHOMETRIC  
PROPERTIES OF OUTCOME-BASED QUALITY  
ASSURANCE INSTRUMENTS**
- 2 ANALYSIS OF ACCREDITATION COUNCIL SURVEY**
- 3 ANALYSIS OF COMMISSION ON THE ACCREDITATION OF  
REHABILITATION FACILITIES SURVEY**



## **COLORADO REPORT**

The Colorado site visit occurred September 27-29, 1995. Individuals interviewed included Kerry Stern, Judy Ruth, and Lynne Struxness all of the Colorado Division for Developmental Disabilities. Since the site visit, members of the research team have been in contact with Judy Ruth and Lynne Struxness, the individuals most closely involved with the Colorado Progress Assessment Review (COPAR).

### **OVERVIEW**

In 1986, in accordance with Colorado state law, the State Auditor's Office conducted an evaluation of the then Colorado Division for Developmental Disabilities (DDD). As part of the review, the state law suggested that the progress of individuals should be evaluated. Through a contract with Conroy & Feinstein Associates, the State Auditor's Office contracted for the development of the Colorado Progress Assessment Review (COPAR). The COPAR was administered to a sample of individuals receiving services through DDD; the survey was re-administered approximately one year later to determine progress during the year. The State Auditor's Office recommended to the legislature that the administration of COPAR continue, and that it be funded by the Developmental Disabilities Council (DDC). The DDC funded the COPAR for two years and since that time the COPAR continues to be funded by the legislature.

The data collected include the dimensions of:

- Community inclusion;
- Consumer satisfaction;
- Adaptive skills/independence;
- Behavioral/mental health issues;
- Medical issues;
- Productivity; and
- Decision-making.

The COPAR assessments are conducted by an outside consulting firm that was awarded a contract through a Request for Proposals (RFP) process. Surveyors are trained by Developmental Disabilities Services (DDS) staff. The COPAR is currently completed on a two-year cycle, where in the first year the portions of



the survey dealing with decision-making, satisfaction and activities are completed. In Year two, data collection domains include: self-esteem, friends and relationships, philosophy and activity levels. Data are collected annually to a stratified random sample of individuals both receiving and waiting for services

In each year, a sample is selected from each of the 21 Community Centered Boards (CCB), the entities that contract for or directly provide residential, vocational and case management supports to individuals. In each CCB a sample of 10% or 30 individuals is selected, whichever is larger. Prior to data collection, the DDS checks for representativeness of the sample. Data are then collected and returned to DDS. The data include interviews with individuals receiving and waiting for services, staff supporting individuals (including direct contact staff and case managers) and parents. DDS then issues a statewide report. If requested, raw data are made available to each of the CCBs. In any situation where health and safety concerns are identified, they are immediately communicated to DDS for follow-up attention.

## DESCRIPTION OF THE DATA SYSTEM

The COPAR data are currently maintained by Colorado Developmental Disabilities Services. The data are analyzed by DDS staff and reports are generated on a statewide basis. Data are analyzed using the Statistical Package for the Social Sciences (SPSS). Often during the past several years, specific areas have been targeted for specialized reports. These reports have included an analysis of individuals waiting for services and a system for screening individuals into service need classifications. In addition, responses using the COPAR were solicited from 1000 people in the general population, facilitating comparisons between those 1000 individuals and individuals receiving services and supports through DDS.

## RELIABILITY

Reliability data have not been collected on the COPAR in many years. Surveyor staff receive training each year that is primarily conducted by DDS staff. The assumption is that the training increases inter-rater reliability.

Because reliability measures have not been determined in several years, the Temple University Institute on Disabilities (IOD) has developed a method to establish inter-rater reliability of the instrument. In order to do so, the COPAR

was administered to 28 individuals currently residing in residential settings in Pennsylvania; 10 in a large, public ICF/MR; 10 in a large, private ICF/MR; and 8 in a small, private ICF/MR. Within one month, the COPAR was collected again by a different rater from the IOD, utilizing the same individuals as respondents. Training of the reviewers was done by IOD staff, utilizing training materials developed by DDS.

This has been a time consuming endeavor requiring the approval of the Pennsylvania Office of Mental Retardation, the two large facilities and one non-profit agency. Data collectors have been trained to collect the COPAR data in addition to the Temple University Behavior Development Survey in these various locations. Raters have been identified as Rater 1 and Rater 2 for the purpose of comparing the inter-rater reliability of this instrument. There was less than one month between the data collected by Rater 1 and Rater 2 at the same facility about the same 28 individuals. Data collection was completed by the end of February, 1996.

The results of the reliability study were as follows:

Scale	Correlation
Relationship Index	.83**
Rights Index	.58*
Esteem Index	.84**
Talents and Capacities Index	.85**
Safety Index	.55*
Decision Index	-.01

\*p=<.01

\*\*p=<.001

As the data in the table show, with the exception of the Decision Making Index, the scales of the COPAR demonstrate inter-rater reliability within acceptable ranges. The decision-making index is a new scale that was developed for the 1995 administration of the COPAR. It is clear that more training is needed to produce reliable information in that area.



## CONCURRENT VALIDITY

Developmental Disabilities Services has not established concurrent validity between the COPAR and other instruments. However, the Vineland Scales of Social Maturity have been collected for 28 individuals. Although these data have not been analyzed in relation to the COPAR, Temple is in possession of the data and has evaluated the feasibility of using the Vineland data to establish concurrent validity with the COPAR. However, because Temple University BDS data were also collected, the Study Team decided to proceed with the analysis of those data instead. The Temple University Behavior Development Survey (BDS) was administered to 28 individuals at the same time COPAR data were collected.

Once the data were collected, scales were calculated on the Temple University BDS and compared to the scales calculated for the COPAR. A Correlation matrix using Pearson Correlation coefficients was produced to examine the relationships between the indices produced by the two instruments. The results of the analysis follows.

COPAR Scales	Temple University BDS Scales		
	Social Network Analysis	Dignity	Adaptive Behavior
Relationship Index	.83**		
Rights Index		.44	
Esteem Index			.64**
Talents and Capacities Index			.74**
	Consumer Satis.	Individualization	Self-Deter.
Talents and Cap. Index	.59*		
Esteem Index	.70**		
Rights Index		.76**	.47

\*  $p < .01$

\*\*  $p < .001$

As the above table shows, the COPAR scales are measuring similar dimensions to those of the Temple University BDS, indicating a strong degree of concurrent validity. As stated in the reliability section, the one scale that appears to be problematic is the decision-making index, which is not correlated with any of the Temple University BDS scales. More work needs to be done in this area.



## **APPLICABILITY**

The COPAR instrument has been used only in services provided by or contracted through the CCBs. Therefore it has not been used in ICF/MR facilities operated by the State (in the Regional Centers) or in private ICFs/MR. The data collected in Pennsylvania has assessed the applicability of the COPAR in settings serving individuals with the most severe disabilities. These data were analyzed anecdotally to determine the extent to which the COPAR instrument can be used in a variety of settings and for people with the most severe disabilities. Data collectors reported that there were no issues related to collecting data for people with the most severe disabilities, other than the fact that data collection using the COPAR is time consuming. When collecting these data in a large facility, the time required to complete the assessments can become burdensome.

In addition, because the COPAR has not been collected in Colorado in quite awhile, the Study Team contracted with the same firm who collects COPAR data in Colorado for some additional data collection. In order to have comparative outcome data for the Health and Safety portion of the study, the IOD contracted with the market research firm to collect COPAR assessments for those individuals for whom Temple University Health and Safety data had been collected. This effort included 34 individuals, 14 of whom were residents of a large, public ICF/MR. The data indicate that those individuals experience severe disabilities including medical complexities and behavioral challenges.

## **DISCRIMINANT VALIDITY**

COPAR data were requested from the Colorado Developmental Disabilities Services. These data have been received and have been analyzed by Temple staff to determine the discriminant validity of the instrument. A test-retest file from 1992 and 1993 was sent that included 781 cases for analysis. The most recent data (1993) were used for the analysis.

In order to assess the discriminant validity of the instrument, a discriminant function analysis was performed. The purpose of discriminant function analysis is to statistically distinguish between two or more groups. To distinguish between groups a collection of discriminating variables are selected, that measure characteristics on which the groups are expected to differ. Based on discussions among the Study Team, it was decided that the two variables to be used as discriminating variables would be level of disability (mental retardation) and living arrangement. The extent to which differences on the COPAR can be

explained by the discriminating variables was assessed. The outcome indices that were examined for purposes of this part of the study included:

- 1) Community Activity Index - including items such as whether individuals shopped for groceries, visited a museum, cooked or prepared meals in the past two weeks;
- 2) Self-Esteem Index - including items such as whether the individual has enough things to do around the house, whether people in the home boss them around, whether individuals feel that what they do during the day is important to them and to others;
- 3) Rights Index - including items such as whether there are places in the home that the individual cannot get to due to mobility problems, whether the individual can be alone when they so choose, whether there are rules in the home;
- 4) Relationship Index - including items such as whether the individuals have friends, whether the individuals have romantic or intimate relationships, how well the individual gets along with others; and
- 5) Decision Index - including items such as who chooses what the individual eats, who chooses the decorations in the individual's room, who decides how personal money is spent.

For each of these indices, a discriminant function analysis was performed using the discriminating variables of level of mental retardation and living arrangement, to see whether group membership (for both level of mental retardation and type of living arrangement) discriminated scores on the five outcome scales. For purposes of this study, the living arrangement variable was collapsed from the original 16 categories to three categories which are: individual setting, including own home, family home; group setting, including group home or apartment; and, institutional setting, which includes regional centers and nursing homes. For purposes of this analysis the breakdown of the population by type of setting is as follows:

Type of Setting	Frequency	Percent
Individual Setting	449	61%
Group Setting	213	29%
Institutional Setting	79	11%
Unknown	40	Missing
Total	781	

Level of mental retardation for the group is as follows:



Level of Mental Retardation	Frequency	Percent
Not Retarded/Mild	292	39%
Moderate	181	24%
Severe	144	19%
Profound	126	17%
Unknown	38	
Total	781	

The first set of analyses examined the extent to which level of mental retardation was successful in discriminating between scores on the outcome measures. One of the ways to interpret a discriminant function analysis is that once a set of variables is found which provides satisfactory discrimination for cases with known group memberships, a set of classification functions can be derived which will permit the classification of new cases with unknown memberships. For example, if the scores on a given outcome variable are known, if the discriminating variables work well, one should be able to determine from which type of living arrangement the individual came as well as their level of mental retardation based on their outcome data. As a check of the adequacy of the discriminant functions, the original set of cases can be classified to see how many are correctly classified by the variables being used.

In the first analyses, where the Study Team was interested in discrimination based on the Rights Index, the following results were obtained:

#### Rights Index

Membership	Predicted Group			
	1	2	3	4
Actual Group Membership				
No MR/Mild	55%	0	27%	18%
Moderate	46%	0	34%	20%
Severe	46%	0	24%	29%
Profound	23%	0	27%	50%

Percent of cases correctly classified = 34.82%



In a variable such as level of mental retardation where there are four categories, one would expect, by chance alone, to correctly classify 25% of the cases. As demonstrated above, approximately 35% of the cases were correctly classified, indicating that the outcome score associated with the rights index can be predicted about 10% better than chance alone by knowing level of mental retardation.

In the next analysis, a discriminant function analysis was run for the rights index with type of living arrangement.

### **Rights Index**

	Predicted Group Membership		
	1	2	3
Actual Group Membership			
Individual Setting	57%	26%	16%
Group Setting	32%	35%	33%
Institutional Setting	18%	30%	52%

Percent of cases correctly classified = 50.34%

In a variable with three categories, such as type of living arrangement, one would predict correct classification of 33% of the cases by chance alone. With the discriminating variable of living type, we are able to classify 17% better than what would be expected by chance alone.

The next set of analyses examined the Relationship Index. The two classification tables for level of mental retardation and living arrangement are as follows:

### **Relationship Index**

	Predicted Group Membership			
	1	2	3	4
Actual Group Membership				
No MR/Mild	58%	0	17%	24%
Moderate	49%	0	19%	32%
Severe	47%	0	14%	39%
Profound	32%	0	10%	58%

Percent of cases correctly classified = 35.33%

### Relationship Index

Actual Group Membership	Predicted Group Membership		
	1	2	3
Individual Setting	68%	8%	24%
Group Setting	53%	6%	41%
Institutional Setting	39%	4%	57%

Percent of cases correctly classified = 49.05%

As the tables show, for the Relationship Index, both of the discriminating variables were able to correctly classify individuals somewhat better than what would be expected by chance alone.

In the next set of analyses, we examined the Esteem Index. The classification tables for the two discriminating variables are displayed as follows:

### Esteem Index

Actual Group Membership	Predicted Group Membership			
	1	2	3	4
No MR/Mild	61%	3%	9%	27%
Moderate	57%	1%	10%	31%
Severe	49%	3%	7%	41%
Profound	29%	0%	0%	71%

Percent of cases correctly classified = 36.53%

### **Esteem Index**

Actual Group Membership	Predicted Group Membership		
	1	2	3
Individual Setting	63%	9%	28%
Group Setting	52%	9%	38%
Institutional Setting	50%	8%	42%

Percent of cases correctly classified = 51.12%

As the tables show, for the Esteem Index, both of the discriminating variables were able to correctly classify individuals somewhat better than what would be expected by chance alone.

In the next set of analyses, we examined the Community Activity Index. The classification tables for the two discriminating variables are displayed as follows:

### **Community Activity Index**

Actual Group Membership	Predicted Group Membership			
	1	2	3	4
No MR/Mild	56%	0%	10%	34%
Moderate	49%	1%	12%	39%
Severe	48%	0%	12%	40%
Profound	32%	1%	3%	64%

Percent of cases correctly classified = 35.31%



### **Community Activity Index**

Actual Group Membership	Predicted Group Membership		
	1	2	3
Individual Setting	54%	19%	27%
Group Setting	49%	20%	30%
Institutional Setting	19%	16%	65%

Percent of cases correctly classified = 45.41%

As the tables show, for the Community Activity Index, both of the discriminating variables were able to correctly classify individuals somewhat better than what would be expected by chance alone.

In the next set of analyses, we examined the Decision-Making Index. The classification tables for the two discriminating variables are displayed as follows:

### **Decision-Making Index**

Actual Group Membership	Predicted Group Membership			
	1	2	3	4
No MR/Mild	55%	16%	17%	12%
Moderate	44%	14%	21%	21%
Severe	28%	15%	21%	36%
Profound	12%	4%	13%	71%

Percent of cases correctly classified = 41.08%

## Decision-Making Index

Actual Group Membership	Predicted Group Membership		
	1	2	3
Individual Setting	65%	14%	21%
Group Setting	34%	15%	51%
Institutional Setting	34%	4%	62%

Percent of cases correctly classified = 50.14%

As the tables show, for the Decision-Making Index, both of the discriminating variables were able to correctly classify individuals somewhat better than what would be expected by chance alone.

In summary, the data indicate that the discriminating variables are able to successfully predict outcome scores on all of the indices developed using the COPAR. The ability to predict group membership is somewhat better than one would expect by chance alone. Philosophically, this is not what one might wish to observe. In other words, as the field of developmental disabilities has moved forward, contemporary notions of outcomes include the belief that all individuals regardless of where they live and regardless of their level of disabilities should be afforded the opportunity to achieve quality outcomes. These data indicate that the achievement of outcomes is, in fact, related to where an individual lives and the level of disability they experience.

As states continue to measure outcomes for all people supported, regardless of where they live or their level of disability, we would expect an increased expectation that all individuals can be supported in achieving quality outcomes in their lives.

## HEALTH AND SAFETY

As of this date, Temple data collectors have collected health and safety information about 35 people in Colorado who live in community and institutional settings. This information was compared to COPAR data collected in these same programs about the same 35 individuals. The most recent COPAR data (collected by the Colorado DDD) is too old (in many cases at least three years) to be valid for comparative purposes. As a result, new COPAR data need

were collected on these individuals. This has been an arduous, time consuming process requiring the agreement and cooperation of the Colorado DDD, the Community Centered Board (CCB) responsible for the 21 individuals in the community and the large public ICF/MR responsible for the 14 individuals living in that facility. In order to collect these data in an expeditious and cost effective manner, Temple subcontracted with the company that has had the contract to collect the COPAR data in the past, to collect these data. This company has been trained by the Evaluation Unit of the Division of Developmental Disabilities in Colorado in the administration of this instrument.

Quality assurance information was obtained from the Division of Developmental Disabilities identifying any regulatory deficiencies for the 21 people in our study living in the community. In addition, information on regulatory deficiencies were reviewed from the Department of Public Health for the same 21 people. For the individuals living in the ICF/MR facility, the OSCAR 3 and OSCAR 4 Reports were obtained from the Colorado Department of Public Health. This was the only additional source of data for these individuals.

All of the above described data have been charted to compare with safety index of the COPAR.

Address	H S																					
	O1	O2	O3	# MED	MEDND	#DOC	UI	BP	SAFESC	SAFE	CDP	CD	QA	QA	COP	HS	RELNDX	RTSNDX	ESTNDX	TALNDX	SAFNDX	DECND
				1.20	0.37	15.6	0.60	0.31	0.60	0.76												
SITE #1	4	4	1	1.60	0.33	23.7	1.00	0.33	2.00	1.00							38	28.33	32.83	10.17	2	13
SITE #2	4	4	1	2.70	0.00	21.3	0.33	1.00	2.00	1.00							51.67	25.33	40.33	13.33	3	13.3
SITE #3	4	4	1	2.00	0.60	27.6	0.60	0.40	2.00	1.00							37.2	28	33	10	2	13
SITE #4				0.00	0.33	10.3	0.33	0.00	0.00	1.00	0	0	1	1			39.33	26	32.33	11.67	2.7	13
SITE #5				0.00	1.00	15.0	2.00	0.00	0.00	0.00	0	0	0	0			48	28	33	15	3	14
SITE #6				0.67	0.00	7.3	0.00	0.67	0.00	1.00	0	1					47.33	28	35.33	14	3	15.3
SITE #7				3.00	1.00	22.0	0.00	0.00	0.00	1.00	0	0	0	0			48	28	40	13	3	17
SITE #8				0.00	0.33	9.0	1.00	0.00	0.00	0.00	0	0	0	0			38.67	28.67	35	11.33	2.3	13.7
SITE #9				0.00	0.00	10.0	0.00	0.00	0.00	0.00	0	1	0	0			38	24	33	10	2	12
SITE #10				0.00	2.00	8.0	4.00	0.00	0.00	0.00	1	0	1	1			39	24	33	10	2	12
SITE #11				0.00	1.00	16.0	0.00	0.00	0.00	1.00	0	0	0	0			37	28	34	10	2	13
SITE #12				0.00	0.00	0.0	0.00	0.67	0.00	0.00	1	3	6	0			45	29.67	33.67	10	2	13
SITE #13				4.00	1.00	15.0	0.00	0.00	0.00	1.00				0	0		49	30	46	14	3	14
SITE #14				3.00	0.00	17.0	0.00	0.00	0.00	1.00	1	1					44	26	37	13	3	16
SITE #15				0.00	0.00	4.0	0.00	0.00	0.00	1.00	0	1	0	0			39	29	34	8	2	12
SITE #16				2.00	0.00	13.0	1.00	0.00	0.00	1.00	0	1	0	0			55	28	40	14	3	15
																	42.2	28.97	34.91	11.4	2.4	13.5

## CONCLUSIONS

The COPAR has been used in Colorado for more than nine years. As a result, a large data base has been amassed, and the Division is able, on an ongoing basis to look at change over time. Unfortunately, the COPAR is used for systemic analysis and is not considered to be a part of ongoing quality assurance efforts in the state. The COPAR is seen more as a research protocol, focusing on particular areas of interest in any given year. These data could be combined with the data



collected through the quality assurance process that includes the Health Department surveys and Division monitoring.

Because of the way in which the COPAR data have been used by the Division, these data are not seen as particularly useful by provider agencies, the Community Centered Boards, consumers or advocates. If resources were available to enable the Division to provide feedback to all stakeholders, these data could be more useful for planning at the local level, and for examining trends over time at the local level.

The COPAR has been demonstrated to be a statistically valid instrument as demonstrated by the reliability and validity studies conducted with the COPAR in Pennsylvania. Given the strong statistical properties of the instrument, the Study Team hopes that the COPAR will continue to be used to measure outcomes for individuals and that the data will become more accessible to families, individuals served and agencies supporting individuals.

# **MASSACHUSETTS REPORT**

## **INTRODUCTION**

The Massachusetts site visit took place on October 5 & 6, 1995 in Boston, Massachusetts.

The Temple staff member who participated in this site visit was Robin Levine. During the site visit, an introduction to the project's goals and activities were described to the administrative staff of the Department of Mental Retardation (DMR). In turn, the DMR staff described the ongoing development and use of the Massachusetts outcome based quality assurance system. The following individuals were interviewed during the site visit and have been an integral part of the ongoing project activities:

- Philip Campbell - Commissioner, DMR
- Mary Cerreto, DMR, Assistant Commissioner, Office of Quality Enhancement (OQE)
- June Rowe - DMR, Assistant Director of OQE
- Gail Grossman - DMR, Assistant Director of OQE
- Ronald Sanfield - DMR, Director of Evaluation, OQE
- Laurie Anderson - DMR, Management Information System
- Therese LaCroix - DMR, Evaluation Unit
- Paul Blake - Wrentham Regional Center, Quality Assurance

## **OVERVIEW - THE SURVEY**

The **Quality Enhancement Survey Tool (QUEST)** is administered by the Office of Quality Enhancement (OQE) of the Department of Mental Retardation. The QUEST process incorporates a combination of Accreditation Council and Title XIX certification processes. The survey includes criteria from the Massachusetts Health and Safety (H&S) Licensing Standards. The conceptual plan of the QUEST process was completed in August 1993. The manual and instrument were completed in January 1994. QUEST has taken the place of licensing and human rights monitoring for all community programs. The agency is the unit of certification based on a 35% sample of individuals. A one-third random sample strategy was designed in order to ensure that

all individuals served by DMR will be surveyed within the first three years of the new system.

Six quality of life (QOL) areas are measured for each individual in the QUEST:

1. Rights and Dignity
2. Individual Control
3. Community Membership
4. Relationships
5. Personal Growth and Accomplishments
6. Personal Well-Being

There is also an evaluation of the organizational structure and process. Outcomes in each quality of life area are defined in observable terms with suggested measures of interpretation. There are a series of questions which provide further clarification on expected outcome measures. Each outcome is rated and receives one of the following six scores:

1. exemplary
2. exceeds
3. achieved
4. partially achieved
5. not achieved
6. not rated

There are four levels of certification based on the ratings in each of the six quality indicators: two years (3 exceeds, all other achieves), one year (all achieves), certification with conditions (any partials or not achieved) and non-certification. In the event that a team member becomes aware of a situation in which the individual is in jeopardy of life, health, safety and/or dignity, the surveyor immediately reports this situation to the agency and the regional director of DMR.

QUEST is conducted by a survey team comprised generally of three people but not fewer than two people. Current surveyors are former Quality Assurance, Human



Rights and Licensing Staff. Other team members may include other DMR staff, citizen volunteers or other human service professionals. Each team member completes an individual rating report prior to a consensus meeting. The consensus meeting synthesizes all the individual reports including commendations and areas in need of improvement for the agency. A team leader is identified who facilitates the consensus process and is responsible for the administrative functions of the survey. Surveyor training is provided through regional supervisors, during the team consensus process leading up to the ratings and, through quarterly surveyors' meetings and case based learning. OQE staff facilitates an intense look at one person's issues (Inquiry Response and Exploration) as an additional method of training.

## DESCRIPTION OF DATA SYSTEM

The data for community residential sites are stored, analyzed and reported by the Evaluation Unit at the Central Office of the Department of Mental Retardation. Data for each region are entered at the five regional offices and transmitted to the Central Office. The first round of data were collected between July 1994 and July 1995. These data were entered using RBase software. The second round of data (since July 1995) is being entered into Access (Microsoft Relational Database). The database was developed by the MIS Unit of Central Office.

There is no cumulative score for the entire QUEST survey. Each domain is scored and reported separately. The following key is used for scoring each measure within the six Quality of Life domains:

Exemplary = 4

Exceeds = 3

Achieved = 2

Partially Achieved = 1

Not Achieved = 0

After each measure is scored, a mean score is determined for each domain. The following is a key for the Quality of Life Outcome Rating based on mean scores:

Exemplary = 3.5 - 4.0

Exceeds = 2.5 - 3.4

Achieved = 1.5 - 2.4

Partially Achieved = .5 - 1.4

Not Achieved = 0 - .4

## **Reliability**

The inter-rater reliability study of the QUEST was conducted in May and June 1994 by the Department of Mental Retardation, Office of Quality Enhancement in the Commonwealth of Massachusetts. The sample was comprised of 30 individuals including six participants in each of the DMR regions. The six participants in each region were selected from different agencies. Individuals receiving day support, residential support, and both day and residential support were included in the study.

In addition to determining inter-rater reliability, several other objectives were identified for this study. Additionally, the study was used to:

1. train staff on specific measures in the QUEST instrument;
2. isolate the outcomes and determine which measures require further clarification to achieve better definition; and
3. to begin to determine the applicability of the instrument in this population.

This study was conducted with one OQE specialist designated as a team member (Rater 1). Rater 1 ratings were used for the agency's certification. Rater 1 also participated in the consensus process. Rater 2 was also an OQE specialist, but was not a member of the team and did not participate in the consensus team process or the determination of agency certification. The purpose of Rater 2 was to shadow Rater 1. Rater 2 evaluated the same individuals and records as Rater 1.

The scores of each measure were compared for Raters 1 and 2. A computer analysis was conducted to determine the reliability of the ratings. The reliability coefficients for all 30 individuals were analyzed. A difference of more than 1.0, was defined as evidence of inter-rater unreliability. Overall, the QUEST instrument was rated at 72.7

% agreement. This indicates that the QUEST instrument is reliable. The following is a table which displays the individual measures and the percent agreement between Rater 1 and Rater 2.

Measure	% Agree
Home is safe	77%
I am safe at home	77%
Work is safe	92%
Free from abuse, neglect and mistreatment	73%
Health services are responsive	77%
Maintain good health	77%
Economic resource meet needs	75%
People are respectful	85%
I look good to myself and others	88%
Life situation supports culture and religion	65%
Home reflects my personal taste and interest	73%
Have access in and around home and work	73%
Home, work and free time reflect value by the community	69%
Rights are protected	69%
Safeguards for limitations in life	65%
Privacy	81%
Support to exercise and safeguard rights	65%
Need for fiduciary is reviewed regularly	69%
Access to personal information is limited	84%
Primary decision maker	77%
Communicate needs and preferences	85%
Like where live	73%
Like where work	88%
Other options for work	96%
Choose free time	88%
Opinions are basis of action	65%
Participate in community life	73%
Part of workplace culture	92%
Contribution to community	34%
Satisfying and meaningful ties	58%
Ways to meet other people	38%
Make and sustain friendships	50%
Intimacy is respected and supported	54%
Develop personal goals	77%
Develop skills for self reliance	81%
Working toward goals	77%
Receive support to achieve personal goals	50%



The two measures of least agreement between Rater 1 and Rater 2 were Contribution to Community (34%) and Ways to Meet Other People (38%). These data suggest that further training needs to be provided to reviewers on the interpretation and scoring of these two measures.

## **Concurrent Validity**

The QUEST instrument has not previously been validated with other instruments. In order to accomplish this, the QUEST survey data need to be compared with data collected by an instrument with proven statistical properties. The original idea for Massachusetts was to bring trained QUEST surveyors to Pennsylvania to administer the QUEST to people in the Philadelphia area for whom data had been collected using a statistically proven instrument. Due to the fact that the QUEST requires a team rating and takes several days to complete, the Study Team determined this to be an ineffective method in terms of cost and time. Rather, we asked the Commissioner of DMR to approve the training and hiring of a data collector to collect the Temple University Behavior Development Survey (BDS) in Massachusetts. Approval from the Commissioner for this continued data collection in Massachusetts was received the first week of January 1996. A data collector was hired and trained to collect these data. Additional permission and consent was needed from the individuals in the specific community agencies in which data would be collected. The agency that agreed to participate obtained the permission of each individual in the study for Temple to collect this information. Upon receiving the various consents, the Temple University Behavior Development Survey was administered in February 1996 to 30 individuals (21 people living in six community residences and 9 people living in one ICF/MR) who have QUEST data in the Massachusetts state system.

Unfortunately, because there were only agencies surveyed, producing two scores, the amount of variance was not sufficient to perform conventional concurrent validity analyses. Although the TEMPLE BDS was collected for 30 individuals, QUEST scores are produced for an entire agency; therefore all 21 individuals living in community settings received one score; similarly all nine individuals living in the ICF/MR received the same score. As an alternative, score on the two sets of instruments were converted to percentages, and areas of commonalty were compared. The following table displays these data:

MA Domain		BDS Domain	
	1. Rights/Dignity	Dignity	
Site 1	50%	95%	
Site 2	50%	100%	
	2. Individual Control	Self-Determination	
Site 1	25%	52%	
Site 2	50%	70%	
	3. Community Membership	Integrated Activity	
Site 1	0	39%	
Site 2	49%	70%	
	4. Relationships	Social Network Analysis	
Site 1	25%	6	
Site 2	27%	17	
	5. Personal Growth		
Site 1	50%		
Site 2	49%		
	6. Personal Well-Being		
Site 1	50%		
Site 2	48%		

Again, because the QUEST items were scored on a scale of 0 through 4, with 0 meaning not accomplished and 4 meaning exemplary, there was not enough variance in the range of scores as there was in the TEMPLE BDS. Therefore, the comparative data are not as meaningful as one might have hoped. As the table above demonstrates, for the last two QUEST domains, personal growth and personal well-being, there were not items from the TEMPLE BDS that were readily comparable. On the first domain, rights and dignity, there was no difference between the two sites (large ICF and community) nor between the data on the TEMPLE BDS domain of dignity. However, QUEST rated the sites as 50% of the possible scale, while the TEMPLE BDS rated the scale at close to the top of the scale. For individual control, Site 1 received a low score and Site 2 a mid-range score; on the HCFA index the spread between the two sites was the same, but the scores for both sites were higher than the QUEST scores. In terms of community



membership, again Site 1 scored lower than Site 2; a pattern similar to that found with the BDS. Again, however, the QUEST scores on this domain were significantly lower than the TEMPLE BDS scores. Finally, we reported scores on the QUEST Relationships Index and compared them to the TEMPLE BDS Social Network Analysis. On this domain, however, the TEMPLE BDS scores could not be converted to a percent as the raw data are based on actual number of relationships. Therefore, we can only address directional similarities. As the data show, in Site 1 the relationships score was slightly higher than for Site 2; the difference was a bit greater on the scores on the TEMPLE BDS.

In summary, the concurrent validity study using the QUEST instrument provided the Study Team with a conceptual framework for a more thorough study. However, given the resources that would have been necessary to complete a thorough concurrent validity study, which would have required visits to numerous sites, such a study was impossible to complete during this project. Hopefully more attention will be focused on this effort by the State of Massachusetts in the future.

## **Applicability**

The QUEST was administered at an ICF/MR facility by regional center staff as a pilot to determine the feasibility of utilizing an outcome-based, person-centered quality assurance system in large facilities where people with severe and multiple disabilities live. In implementing the survey process many staff began and remained skeptical about the use and value of an outcome-based system for this group of people. Others began with caution and were later able to understand the value of this new orientation to people's preferences, rights and dignity. As might be expected, the ratings in particular QUEST domains that depend on access to community resources were low. The rating for community membership was "not achieved" and the ratings for relationships and individual control were "partially achieved". In summary, the ICF/MR pilot demonstrates that the QUEST is applicable across a variety of settings.

The ICF/MR Facility Summary Report resulted in a plan of correction based on the findings. In this way the QUEST was being used as a quality enhancement tool. Similarly, the QUEST is being used as part of the internal monitoring system in other state facilities. Training of Qualified Mental Retardation Professionals in these facilities is underway in order to educate and prepare the staff and programs for this type of survey process. QUEST data are stored at the various regional centers and are not currently analyzed by the Department of Mental Retardation.



## **Discriminant Validity**

The staff of the Evaluation Unit of DMR has provided Temple staff with the QUEST data collected between July 1994 and June 1995. These data and data from an ICF/MR facility have been analyzed to determine the instrument's discriminant validity in areas such as ability to predict living arrangements based on individual ratings. Unfortunately, the QUEST data base does not have discriminating variables such as level of disability. Because the QUEST is only used in community settings, there is no variability in the variable. Even using the data collected on the Temple BDS, there were only two sites and it would have been virtually impossible to complete the analysis. Therefore, it was impossible to complete the discriminant validity portion of the study.

## **Health and Safety**

In order to demonstrate the degree to which the QUEST guarantees and protects the health and safety of individuals, a comparison study was conducted based on both existing and new data. The new data were collected by a Temple data collector using the Temple University Health and Safety Issues Instrument. Information was collected on site for 30 individuals (21 people living in six community residences and 9 people living in one ICF/MR) who have QUEST Health and Safety data in the Massachusetts state system. In addition, information was obtained from the Investigations Unit of DMR identifying any allegations of abuse or neglect for the same 30 people in our study. The Investigations Unit was the only additional source for information on individuals residing in the community because the QUEST has taken the place of all other methods of monitoring, licensing and certification. For the individuals living in the ICF/MR facility, the OSCAR 3 and OSCAR 4 Reports were obtained from the Massachusetts Department of Public Health. This was the only additional source of data for these individuals.

All of the above described data have been charted to compare with Quality of Life Area #6 (Person Well-Being) of the QUEST. This QOL area includes three measures of quality which are individually rated according to the 0 - 4 range described in the introduction to this section. In order to obtain the overall score for this Quality of Life Area, the three measure scores were added and an average score was determined. The reports received from the Investigations Unit were reviewed and the number of health and safety issues were counted. This raw score is recorded in the Investigations column. The attached table displays the findings from all the sources previously described.

The study team conducted non-parametric correlations which produced the Spearman Correlation Coefficients in order to analyze the various health and safety data. Significant correlations were found between the Medical Needs Scale of the Temple University Health and Safety issues instrument and the overall score of the QUEST QOL Area #6 (described above). Additionally, a significant correlation was found between the Behavior Plan Scale of the Temple University Health and Safety issues instrument and the total score of the QUEST instrument.

These findings must be interpreted with extreme caution due to the lack of variance in the number of cases analyzed and the small range of actual scores. While data was collected for 30 individuals, this represents scores for only four different agencies due to QUEST's method of rating and scoring agencies not individuals. Therefore the scope of the analysis is quite small with only four cases. Secondly, the actual scores do not represent the full range of scores. For instance, the range of possible scores for the Medical Needs Scale of the Temple University Health and Safety issues instrument is from 0 - 3. The actual scores reported ranged from 0 - .8. The range for possible QUEST scores is from 0 - 4. The actual range for the total QUEST score in this study was from 1.5 - 2. From these data, it appears that health and safety measures are not necessarily related to outcome measures of the QUEST.

Type of Residence	O1	O2	O3	QUEST	# INVEST	# MED	MEDND	#DOC	UI	BP	SAFESC	SAFE	QUEST H&S
Community Provider #1	N/A	N/A	N/A	1.91	1	1.71	0.00	12.00	0.57	0.28	2.00	2.00	1.50
Community Provider #2	N/A	N/A	N/A	1.81	0	0.75	0.00	9.50	0.00	0.00	0.00	1.00	1.84
Community Provider #3	N/A	N/A	N/A	1.94	0	1.00	0.80	8.70	0.30	0.60	0.40	1.30	2.08
ICF/MR	4	2	1	1.33	0	1.22	0.56	8.67	0.22	0.00	1.67	1.00	2.00
TOTAL						1.20	0.43	9.57	0.30	0.27	1.10	1.33	
4391 INV.				77	83	0.00	2.00	7.00	0.00	0.00	0.00	0.00	0.00

## Conclusions

The Massachusetts quality enhancement system has many strong components. It is person-centered and based in quality of life outcomes with observable and measurable criteria. It has proven inter-rater reliability and is applicable to settings serving people with the most significant disabilities. More work needs to be done in the area of concurrent validity to ensure that the QUEST is measuring dimensions that are valid and comparable to other acceptable instruments in the field.



The QUEST is also utilized as a mechanism to provide technical assistance to providers and to provide information to the Operations Division of DMR for contracting with providers. The survey team approach offers a broad perspective of experiences and the consensus process supports the proven reliability of the survey. The survey can take several days to complete depending on the size of the agency and the number of individuals to be observed. The time factor can be seen as both a positive and negative attribute of the QUEST. Positively, it seems that a surveyor would have enough time to observe and gather information, thereby formulating a comprehensive evaluation of the individual's quality of life. However, in terms of replicability, the time and resources needed may be too much of a commitment in this era of downsizing. This quality enhancement system seems to include many of the quality outcomes judged to be important in the lives of people with developmental disabilities. As the system has only been in effect for two years, it is not possible to judge the long term effect of the QUEST on the overall quality of services and supports to people supported through the Massachusetts Department of Mental Retardation.



1. The first part of the document discusses the importance of maintaining accurate records of all transactions. It emphasizes that this is crucial for the company's financial health and for providing reliable information to stakeholders.

2. The second part of the document outlines the procedures for handling customer inquiries. It states that all inquiries should be handled promptly and professionally, and that the company should strive to provide the best possible service to its customers.

3. The third part of the document discusses the company's policy on employee conduct. It states that all employees are expected to adhere to a high standard of ethical behavior and to follow the company's policies and procedures.

4. The fourth part of the document discusses the company's commitment to environmental sustainability. It states that the company is committed to reducing its carbon footprint and to using sustainable materials in its products and packaging.

5. The fifth part of the document discusses the company's commitment to social responsibility. It states that the company is committed to supporting the community and to promoting the well-being of its employees.

6. The sixth part of the document discusses the company's commitment to innovation. It states that the company is committed to developing new products and services that meet the needs of its customers.

# **MISSOURI REPORT**

## **Introduction**

The Missouri site visit took place on October 17 through October 19, 1995. An introductory meeting was held in Kansas City between project staff and key State and provider agency staff for the purpose of being briefed on the intent of the HCFA project as well as providing project staff with an overview of the quality assurance system for individuals with developmental disabilities. Temple University's Institute on Disabilities (IOD) staff, Kathy Miller met with the University of Missouri at Kansas City's Institute on Human Development staff to determine the extent of the statistical testing applied to the outcome measure survey instrument. During the site visit IOD staff also collected health and safety information on 30 individuals receiving residential support from the Division of Mental Retardation / Developmental Disabilities (DMR/DD) in the St. Louis area. The following individuals were interviewed during the site visit:

- Greg Kramer, DMH/DMR/DD, Director
- Kate McClain, DMH/DMR/DD, Quality Enhancement Coordinator
- Meg Hutsler, DMH/DMR/DD, Quality Enhancement Team Leader
- Donna Haley, DMH/DMR/DD, Quality Enhancement Surveyor
- Cori Brown, University of Missouri at Kansas City, Project Consultant
- Christine Rinck, Ph.D., University of Missouri at Kansas City, Research Director

Contact with key individuals in Missouri by IOD staff was continuous throughout the project as systems for analysis of the quality outcome measures were developed and the need for securing additional information was identified.

## **Overview**

Missouri has three quality assurance options for agencies providing supports to people who have developmental disabilities. They are:

- The Certification Project, a voluntary quality enhancement option for agencies providing supported living programs under the HCB Waiver. Agency reviews under this project began in July of 1995. This review is done every two years. Beginning in July of 1996, the Missouri Advocates for Individuals with Developmental Disabilities (MOAIDD), a group of interested self-advocates and advocates, will review the Certification Project Agencies during the second year of the two year cycle.
- A recently enacted Missouri law allows an agency who chooses not to participate in the Certification Project to select either the CARF or AC accreditation process. An agency who attains either CARF or AC accreditation is granted deemed status under the Certification Project.
- For those agencies providing non-waiver residential services, e.g., ICFs/MR, traditional licensure under the auspices of the Department of Mental Health is done on an annual basis.

The Certification Project is a Quality Enhancement model based on the following four principles: Community Membership; Self Determination; Rights; and Meeting Basic Needs. The instrument used to measure quality outcomes is based on these four principles. Various outcomes are identified under each principle which are further delineated into standards. These standards are scored on a four point scale by the QA Survey Team. The QA Survey Team is comprised of the Team Leader, a Credentialed Team Member and/or a Team Member in Training, and interested Observers. The Team Leader is employed by the Missouri Department of Mental Health-Division of Mental Retardation and Developmental Disabilities. This individual has ultimate responsibility for carrying out the on site survey process, and reports directly to the Director of the DMR/DD. The Credentialed Team Member has completed all training and experiential requirements and is responsible for assisting the Team Leader in the survey process. The Team Member(s) in Training participate on survey teams in specialized roles as part of their experiential training. Observers are those individuals who are interested in experiencing the enhancement process but may not be willing or able to make a commitment to the time entailed in becoming a team member.

An average score of the standards is obtained for each outcome. The end result is an agency score for each of the outcomes. Additional feedback to the Agency includes an enhancement plan which contains specific recommendations, timelines, and resources. All agency waiver programs are evaluated, and a sample of 10% of the consumers are interviewed.



The consumer/advocate component of the Certification Project overseen by MOAIDD is proposing to use an adapted version of OKAIM from Oklahoma and MOVERS from the state of Washington to conduct their quality outcome assessments.

## **Description Of Data System**

State QA Team Leaders are responsible for compiling and maintaining the outcome data collected during an agency survey. Sixteen Agencies have gone through the Certification Project survey process. Data from these 16 surveys were used in our analysis of the Discriminant validity portion of our study as well as the health and safety data comparison.

## **Reliability**

A pilot reliability study, Medicaid Waiver Certification Standards A Pilot Reliability Test, was completed on the Certification Project's survey instrument in October, 1995. The principal investigator of the study was Christine Rinck, Ph.D., of the Institute of Human Development, University of Missouri at Kansas City, the State's University Affiliated Program. There are plans to conduct reliability studies on an ongoing basis.

The following section summarizes the analysis of the reliability study.

A four point scale is used in rating an agency's ability to meet the standards under each of the identified outcomes in the Certification Project's survey. The scale involves rating the standards as a) passively prohibitive; b) enabling; c) enhancing; and d) optimally enhancing.

The accuracy of reliability was judged on the criteria that the scores of the two surveyors had to be within one point of each other in order to classify their ratings as correct. For example, if one surveyor rated an item 1 "passively prohibitive" and the other rated an item 2 "enabling" then this answer was considered to be correct. However, if one rated an item 1 "passively prohibitive" while the other rated an item 3 "enhancing", then the answer was classified as a mismatch and hence, incorrect.

In addition, a Cronbach's alpha score was computed for each of the scales. The objective of this statistical measure is to determine the extent to which the items

on a scale are closely related to each other. 1.0 is a perfect score. Therefore, the closer the score is to 1.0, the higher is the confidence with which the findings can be accepted.

The following is a synopsis of the Cronbach's alpha score derived for each scale employed to measure quality outcomes.

### **Section 1.0**

#### **Community Membership**

1.1 Promoting Acceptance Through Community Involvement: .97

1.2 Supporting and Promoting Relationships: .94

1.3 Supporting and Promoting Contribution: .76

1.4 Facilitating and Enhancing Communication: .84

1.5 Facilitating Community Involvement: .99

### **Section 2.0**

#### **self-determination**

2.1 Promoting Self-Esteem Through Positive Self-Expression: .97

2.2 Maximizing Individual Choice and Decision Making: .60

2.3 Facilitating Empowerment: \*

2.4. Person Centered Planning: .94

### **Section 3.0**

#### **Rights**

3.1 Assuring Human Rights, Dignity, and Respect: .96

3.2 Assuring Legal Rights: .94

### **Section 4.0**

#### **Meeting Basic Needs**

4.1 Assuring and Promoting Good Health: .94



## 4.2 Assuring Individual Safety: .97

*\*Alpha not computed*

### Conclusion

Thus, with the exception of the scale on maximizing individual choice and decision making, the study indicates high reliability.

### Concurrent Validity

A Content Validity Study was completed in July of 1994. The study, Missouri Medicaid Waiver Certification Standards: A Validation Study was conducted by Christine Rinck, Ph.D., Director of Research, Institute for Human Development, University of Missouri-Kansas City, a University Affiliated Program. This study was achieved through the following three activities. The first activity brought a focus group of 14 persons with developmental disabilities together to discuss the importance of the standards. A second activity consisted of convening a group of 15 families with children/adult family members with developmental disabilities to identify standards that were unclear and those that did not reflect the outcomes. The third activity identified six professionals throughout the nation who have extensive experience in the field of developmental disabilities, and asked them along with the family members who took part in the focus group to rate the standards. This third group rated each standard on a five-point rating scale based on its relationship to the outcomes and principles, and identified the standards most and least reflecting the outcomes. This analysis allowed the project to refine its survey instrument prior to implementing the survey portion of the Certification Project.

No concurrent validity study of the Certification Project's survey instrument has been done in Missouri. The IOD conducted this study to establish the extent to which the Certification Project's outcome instrument and the Temple University Behavior Development Survey (BDS) are measuring the same underlying dimensions. In considering where to conduct the concurrent validity component of the quantification studies we considered the concentrated effort made by the Certification Project steering committee to put their resources into multi-faceted values-based training during the two years preceding the start of the agency surveys. Survey team training and experiential requirements are extensive and are designed to be individualized according to the needs of each team member. Due to the professional development design of the training requirements, it would be too difficult to duplicate the Certification Project survey process in Pennsylvania.



The concurrent validity study was conducted in Missouri by administering the TEMPLE BDS to a sample of 33 individuals receiving supports from 5 agencies who have gone through the Certification Project agency survey process. Staff from the Institute for Human Development, UMKC/UAP and the DMH/DMR/DD Certification Project administered the BDS instruments in Missouri. Training on the use of the TEMPLE BDS was completed over the telephone by IOD staff. Consent was obtained for the individuals for whom information on the TEMPLE BDS was collected.

Because there were only 5 agencies included in concurrent validity data set, many of the correlation coefficients were meaningless. We are instead doing a more qualitative analysis by comparing the variables for each of the sites included. The data is summarized in the following table.

1. COMM. MEMBERSHIP INTEG. ACTIVITY (PA)		
SITE 1	42	62
SITE 2	55	68
SITE 3	20	63
SITE 4	11	61
SITE 5	51	53
2. SELF DETERMINATION		
SITE 1	53	51
SITE 2	49	63
SITE 3	31	50
SITE 4	23	61
SITE 5	50	56
3. RIGHTS		
SITE 1	54	100
SITE 2	58	100
SITE 3	56	98
SITE 4	43	100
SITE 5	78	97
4. MEETING BASIC NEEDS		
SITE 1	62	
SITE 2	100	
SITE 3	48	
SITE 4	51	
SITE 5	71	

## **Applicability**

The Certification Project outcome instrument was designed to measure outcomes of supports and services provided under the HCB waiver to persons with developmental disabilities. The survey portion of the project is not being used at this time in any of Missouri's six public ICFs/MR facilities or 16 private ICFs/MR facilities. We were not able to duplicate the Certification Project's survey process in Pennsylvania due to the extensive training requirements of the surveyors. These two factors, therefore prevented us from establishing the applicability properties of the Certification Project's survey instrument in settings serving individuals with the most severe disabilities.

## **Discriminant Validity**

The Certification Project Agency Survey Data contains survey scores of 16 agencies. This data is what was used to determine the extent to which the survey instrument can successfully discriminate between individuals based on their scores. An example would be whether, based on Certification Project Agency Survey Data scores, residential settings can be predicted. In order to analyze the discriminant validity of the instrument the most recent Certification Project Agency Survey data have been forwarded to Temple. The data base contained only the Certification Project Agency Survey Data and, since it was agency based contained no individuals characteristics to predict. The analysis have been performed by combining the individual data from the concurrent validity BDS data collected in Missouri with the Certification Project Agency Survey data. This combined data file contained data for 33 individuals.

In order to assess the discriminant validity of the instrument, a discriminant function analysis was performed. The purpose of discriminant function analysis is to statistically distinguish between two or more groups. To distinguish between groups a collection of discriminating variables are selected, that measure characteristics on which the groups are expected to differ. Based on discussions among the Study Team, it was decided that the two variables to be used as discriminating variables would be level of disability and living arrangement. The extent to which the outcome instrument's scales can discriminate between and predict level of disability and type of living arrangement was assessed. The outcome indices that were examined for purposes of this part of the study included:

- Community membership;
- Self determination;



- Rights; and
- Meeting basic needs.

For each of these indices, a discriminant function analysis was performed using the discriminating variables of level of disability and type of living arrangement, to see whether group membership discriminated scores on the five outcome scales. For purposes of this study, the living arrangement variable includes: **group home/waiver/foster family, and supervised apartment.** For purposes of this analysis the breakdown of the sample by type of setting is as follows:

Type of Setting	Frequency	Percent
Group Home/Waiver/Foster	7	21%
Supervised Living	26	79%
Total	33	

Level of disability for the group is as follows:

Level of disability	Frequency	Percent
Mild	18	55%
Moderate/severe/profound	15	45%
Total	33	

The first set of analyses examined the extent to which type of living arrangement was successful in discriminating between scores on the outcome measures. One of the ways to interpret a discriminant function analysis is that once a set of variables is found which provides satisfactory discrimination for cases with known group memberships, a set of classification functions can be derived which will permit the classification of new cases with unknown memberships. For example, if the scores on a given outcome variable are known, if the discriminating variables work well, one should be able to determine from which type of living arrangement the individual came. As a check of the adequacy of the discriminant functions, the original set of cases can be classified to see how many are correctly classified by the variables being used. The table below lists, by outcome measure, the percent of cases correctly classified using type of placement as a discriminating variable.



Percent of Cases Correctly Classified  
Using Type of Living Arrangement

Community membership	69.70%
Self determination	69.70%
Rights	51.52%
Meeting basic needs	69.70%

In a variable such as living arrangement where there are two possible categories, one would expect to correctly predict group membership 50% of the time by chance alone. As the table above demonstrates, on each of the outcome variables, we were able to predict outcome scores by living arrangement more often than would be expected by chance alone on all outcome measures except Rights.

For the first two standards, prediction of group membership was 20% better than by chance alone. For the third standard, Rights, prediction of group membership was the same as change alone. For the fourth standard, Meeting basic needs, prediction of group membership was 20% better than by chance alone.

The second set of analyses examined the discriminating properties of the variable, level of disability. The table below lists, by outcome measure, the percent of cases correctly classified using level of disability as a discriminating variable.

Percent of Cases Correctly Classified  
Using Level of Mental Retardation

Community membership	63.64%
Self determination	63.64%
Rights	51.52%
Meeting basic needs	54.55%

Again, in a variable with two categories, one would expect correct classification by chance alone in 50% of the cases. As the table demonstrates, the outcome scores correctly predict group membership by level more often than would be expected by chance alone, for three of the four outcome indices.

In summary, the discriminant validity of the Missouri outcome instrument was a little better than would be expected by chance alone, for both type of living arrangement and level of disability.

## **Health And Safety**

Health and Safety data were collected on 30 individuals residing in five living arrangements in the greater St. Louis area. Four agencies were represented in this sample.

Two of the four agencies have gone through the Certification Project agency survey, and the remaining two will be completed in the current fiscal year. The health and safety information was gathered by IOD staff on October 18 and 19 using the Temple University Health and Safety Issues Instrument, developed by the Temple University Institute on Disabilities. The Missouri quality outcome instrument scores will be compared with the data collected on the health and safety instrument.

The Study Team obtained and reviewed the reports from the Department of Mental Health's Bureau of Quality Improvement on their review of the five sites where data was collected using the Temple University Health and Safety Issues instrument. The licensing surveys were done the year before the Certification Project was designated as the certifying body for these sites. Our intent was to compare the results of the Temple University Health and Safety Issues survey with the licensing reports. It was not possible to make any substantial comparisons between the health and safety data collected as part of the study via the Temple University Health and Safety Issues instrument and the State licensing results. The Study Team found that state licensing is based on nine value domains and are reported in the summaries in a narrative form that is not quantifiably rated. Therefore, because the licensing information is too qualitative in form we are unable to analyze this information and compare it with the Temple University health and safety data.

The Certification Project's outcome data are reported by agency scores. A four point scale is used in rating an agency's ability to meet the standards under each of the identified outcomes in the Certification Project's survey. The scale involves rating the standards as: 1 = passively prohibitive; 2 = enabling; 3 = enhancing; and 4 = optimally enhancing. An average score is then assigned to each of the four outcome areas headings. As previously discussed in the Overview Section, these four outcomes are Community Membership, Self Determination, Rights, and Meeting Basic Needs.



The average scores from these four sections as well as the health and safety data were analyzed to determine the congruence between the data. The study team conducted non-parametric correlations which produced the Spearman correlation coefficients to analyze both sets of health and safety data. Significant correlations were found between the Neighborhood Safety Scale of the Temple University Health and Safety Scale and three of four outcomes from the Certification Project's outcome instrument. The three outcomes were Community Membership, Self Determination, and Rights.

These findings must be interpreted with extreme caution due to the lack of variance in the number of cases analyzed, the small range of actual scores, and the fact that for the Certification Project, scores are given to facilities, not individuals. While data were collected for 30 individuals, this represents scores from only four different agencies due to the Certification Project's method of rating and scoring. Therefore, the scope of the analysis is limited with only four cases.

PROV	MED	MEDND	DOC	UI	BP	SAFESC	SAFE	S1	S2	S3	S4
17	0.93	0.18	10.1	0.06	0	1.5	1.6				
18	0.2	0.2	12	0.20	0	1	0				
5	2.37	0.25	9	0.87	0.25	0	1	2.7	2.8	3.3	3
6	0	0	3	0.00	0	2	1	2.6	2.4	2.7	4

## Conclusions

Our foremost impression of the Certification Project is in regard to the emphasis in the design and implementation of the project to maximize input from all levels of the population: self-advocates, parents, interested citizens, and all levels of the service/support delivery system. We view this as a very positive aspect of the project insofar that the inclusion of a maximum number of stakeholders validates the process by promoting acceptance of the project. Optimally, this will in turn lead to acceptance of the principles on which the outcome measures are based which will lead to real growth and improvement in individual's lives.

Quantitatively, the collaboration with the UAP is very positive, in that the instrument, whose principles were identified by consensus, was validated by individuals who are experts in the field: individuals with developmental disabilities, family members of children/adults with a developmental disability and professionals in the field of developmental disabilities. The results from the pilot reliability study were strong, and there are plans in place to continually



update the reliability of the outcome instrument. Unfortunately, we are examining the project just as they are getting started so there is not much data to verify at this time.

# **NEW YORK REPORT**

## **Introduction**

The New York site visit took place on September 13 and September 14, 1995. An introductory meeting was held in Albany between project staff and key State agency staff for the purpose of informing state personnel of the intent of the HCFA project as well as providing project staff with an overview of the quality assurance system for individuals with developmental disabilities. Temple University's Institute on Disabilities (IOD) staff members, James Lemanowicz and Kathy Miller met with state staff to determine the availability of a final outcome measure survey instrument and the extent of its use in collecting data. During the site visit IOD staff also collected health and safety information on 30 individuals receiving residential support from the Office of Mental Retardation/Developmental Disabilities (OMR/DD) in Albany and Rome. The following individuals were interviewed during the site visit:

- Thomas Cuite, OMR/DD, Division of Quality Assurance, Deputy Commissioner
- Thomas Articola, OMR/DD, Division of Quality Assurance
- David Picker, OMR/DD, Division of Quality Assurance
- Tom Richards, OMR/DD, Division of Quality Assurance

Contact with the key stakeholders in New York by IOD staff was continuous as systems for analysis of the quality outcome measures were developed and the ongoing need for securing additional information was identified.

## **Overview**

The New York Office of Mental Retardation and Developmental Disabilities (OMR/DD) Division of Quality Assurance (DQA) developed a pilot model to promote quality outcomes in supports and services provided to persons with developmental disabilities known as COMPASS. COMPASS stands for: Consumerism, Outcomes, Management Plan, and Agency Self Survey. COMPASS is a systems approach to quality outcomes. The system is based on the principles of 3IP-Independence; Integration; Individualization; and Productivity.

The Consumerism portion of COMPASS is intended as a means to obtain consumer input in decisions affecting people's lives. The Outcome element of COMPASS refers to the actual tool(s) created to measure quality outcomes. The Management Plan section of the COMPASS system is envisioned to be a plan in which each participating agency would develop their own unique blueprint addressing how their organization would achieve the underlying principles of COMPASS. The Self-Survey element of COMPASS is intended to be an agency created system of self-monitoring. This self-monitoring was originally intended to include only regulatory compliance and later evolved into a means of monitoring the other elements of COMPASS, (i.e., consumerism, management plan, and outcomes).

Our focus in the evaluation of COMPASS is on the Outcome portion of the system. During the first pilot of the COMPASS system, three different outcome instruments were developed by the three service regions in the State. Due to the fact that there was no uniform data collection, we are unable to include any of this information in our data analysis. A single Outcome Review Instrument was developed in September, 1995. This is the tool we analyzed

## **Data System**

New York completed their pilot study of the COMPASS system in September, 1995, which included the Outcome Review. At the end of the pilot study, Outcome Review data was available for 9 individuals. This is not enough data to be useful for statistical analysis.

## **Reliability**

The final Outcome Review instrument was administered to 9 individuals in New York by two individual raters. This number is too small to establish inter-rater reliability, therefore the New York Outcome Review instrument was administered to 28 individuals residing in Pennsylvania Intermediate Care Facilities for persons with Mental Retardation (ICFs/MR); 10 individuals residing in a large private ICF/MR, 10 individuals residing in a large public ICF/MR and 8 individuals residing in several small ICFs/MR. The New York Outcome Review instrument was administered to the same 28 people by two separate data collectors. These two instruments were administered within a month of one another. Data collection was completed at the end of February, 1996.



The results of the reliability study are presented in the following table. Pearson correlation coefficients were calculated for each of the scales on the instrument.

Scale	Correlation
Independence	-.29
Integration	-.08
Individualization	.23
Productivity	.28

As the table shows, none of the correlations were significant. The data collected indicate that the New York instrument is not reliable when tested for inter rater reliability.

### Concurrent Validity

The Temple University Behavior Development Survey Development Survey (BDS) was administered to the same 28 individuals who were administered the New York Outcome Review instrument. The Temple University BDS has established properties of reliability and validity. The data from both instruments were collected and the information obtained from the New York Review Outcome instrument was compared with the data gathered from the BDS to determine concurrent validity.

NY Outcome Index	Temple University BDS Scale	
	Dignity	Self Determination
Independence	.45	.43
Individualization	.42	

As the table demonstrates, there are only three areas of the New York instrument that were correlated with the Temple University BDS; however no area reached statistical significance. The lack of relationships with other scales such as integration and productivity is cause for concern. It is our recommendation that New York continue working on the development of their outcome instrument, checking for reliability and concurrent validity as they progress in development.



## **Applicability**

As mentioned during the Reliability section of this report, the New York Outcome Review instrument was administered in 2 large Pennsylvania based ICF/MR facilities, and 2 smaller community based ICFs/MR. The individuals residing in these living arrangements have a wide range of abilities and physical challenges, and the applicability of this tool to persons with the most severe disabilities was analyzed using this data. The other problems with this instrument need to be addressed if New York intends to use an outcome assessment with individuals with a range of disabilities.

## **Discriminant Validity**

As mentioned in the Reliability and Applicability section of this report, the New York Outcome Review instrument was administered in 2 large Pennsylvania based ICF/MR facilities, and 2 smaller community based ICFs/MR. We have data on 28 New York Outcome Reviews. In its latest data collection for their pilot study, New York only had 9 Outcome Reviews completed. Our original intention was to augment our 28 Outcome Reviews with the 9 New York Outcome Reviews, giving us 37 cases to analyze. However, the data obtained from New York has no residential identifiers which makes it impossible to complete a discriminate between variables.

This portion of the review determines the extent to which the Outcomes Survey can successfully discriminate between individuals based on their scores. An example would be whether, based on Outcomes Survey scores, residential settings can be predicted. In order to analyze the discriminant validity of the instrument the Outcomes Survey data collects in Pennsylvania has been analyzed.

In order to assess the discriminant validity of the instrument, a discriminant function analysis was performed. The purpose of discriminant function analysis is to statistically distinguish between two or more groups. To distinguish between groups a collection of discriminating variables are selected, that measure characteristics on which the groups are expected to differ. Based on discussions among the Study Team, it was decided that the two variables to be used as discriminating variables would be level of mental retardation and living arrangement. The extent to which differences on the outcome instrument's scales can be explained by the discriminating variables was assessed. The outcome indices that were examined for purposes of this part of the study included:



- Independence;
- Integration;
- Individualization; and
- Productivity.

For each of these indices, a discriminant function analysis was performed using the discriminating variables of level of mental retardation and living arrangement, to see whether group membership discriminated scores on the five outcome scales. For purposes of this study, the living arrangement variable includes: group residence -15 people, and ICF/MR, 16 or more people. For purposes of this analysis, the breakdown of the sample by type of setting is as follows:

Type of Setting	Frequency	Percent
Group Residence 4-15	8	29%
ICF/MR 16+	20	71%
Total	28	

Level of mental retardation for the group is as follows:

Level of Mental Retardation	Frequency	Percent
Mild	8	29%
Moderate	4	14%
Severe	7	25%
Profound	9	32%
TOTAL	28	

The first set of analyses examined the extent to which type of living arrangement was successful in discriminating between scores on the outcome measures. One of the ways to interpret a discriminant function analysis is that once a set of variables is found which provides satisfactory discrimination for cases with known group memberships, a set of classification functions can be derived

which will permit the classification of new cases with unknown memberships. For example, if the scores on a given outcome variable are known, if the discriminating variables work well, one should be able to determine from which type of living arrangement the individual came as well as their level of mental retardation based on their outcome data. As a check of the adequacy of the discriminant functions, the original set of cases can be classified to see how many are correctly classified by the variables being used. The table below lists, by outcome measure, the percent of cases correctly classified using type of placement as a discriminating variable.

Percent of Cases Correctly Classified  
Using Type of Living Arrangement

Independence	85.71%
Integration	46.43%
Individualization	78.57%
Productivity	64.00%

In a variable such as living arrangement where there are two possible categories, one would expect to correctly predict group membership 50% of the time by chance alone. As the table above demonstrates, on three of the four outcome variables, we were able to predict outcome scores by living arrangement significantly more often than would be expected by chance alone.

The second set of analyses examined the discriminating properties of the variable, level of mental retardation. The table below lists, by outcome measure, the percent of cases correctly classified using level of mental retardation as a discriminating variable.

Percent of Cases Correctly Classified  
Using Level of Mental Retardation

Independence	35.71%
Integration	21.43%
Individualization	35.71%
Productivity	36.00%

In a variable with four categories, one would expect correct classification by chance alone in 25% of the cases. As the table demonstrates, the outcome scores correctly predict group membership by level of mental retardation more often than would be expected by chance alone, three of the four outcome indices.



In summary, the discriminant validity of the New York outcome instrument is better than would be expected by chance alone, for both type of living arrangement and level of mental retardation. Given the issues with reliability and concurrent validity, this instrument requires further analysis.

## **Health And Safety**

Health and Safety data were collected using the Temple University Health and Safety instrument on 30 individuals residing in three living arrangements in the Albany/Rome, N.Y. area, by IOD staff on September 14 and 15, 1995. Two agencies were represented in this sample. Each of the agencies had been part of the COMPASS pilot project. There are data from the New York Outcome Review instruments for 9 people in the entire state. These 9 individuals live in different regions throughout the state. None of the individuals for whom the Study Team collected data using the Temple University Health and Safety Issues instrument in Albany and Rome were included in this NY Outcome Review instrument sample of 9 individuals.

No individual outcome data were available for any of the individuals residing in the Albany/Rome area where the Study Team was physically able to go to and collect data. The determination was made during the site visit to proceed with collecting health and safety information. This decision was based on the assumption that because COMPASS is a systems approach to attaining quality outcomes we could measure alternate indicators for these COMPASS pilot project sites. In the absence of individual outcome data, it was determined that comparisons could be made between the agency ICF/MR OSCAR results, State licensing results and the Temple University health and safety data.

We made our determination of how well these three Compass sites protects the basic health and safety of the individuals it provides supports to by comparing our data to the agency's ICF/MR survey reports and the agency's state licensing reports, as displayed by the table. In the analysis of the data we conducted non parametric correlations and assessed the Spearman Correlation Coefficients and found no significant correlations. This in part is due to the small number of cases in the study. In addition, it is possible that due to the passage in time since the state collected data, and the difference in the dimensions assessed by the Temple University BDS and the NY licensing and OSCAR data, there are no relationships between the variables measured.



Address	O1	O2	O3	#MED	MEDND	#DOC	UI	BP	SAFESC	SAFE	LS
Site 1	4	1	4	0.8	0.3	15.4	0.3	0	0	0	0
Site 2	4	4	4	3.2	0	14	0.4	0.2	0	0	2
Site 3	4	5	4	0.9	0.4	29.4	0.2	0	0.3	1	0
				1.6	0.3	19.7	0.34	0.04	0.1	0.33	

## CONCLUSIONS

The design of the NY pilot project did attempt to elicit interested party input but relative to other state efforts it wasn't as far reaching as it could be. The DQA surveyors did benefit in that they stated that they felt more connected to the people they had been surveying for all these years; some reviewers had been surveyors for up to 20 years.

Quantitatively, this is a very difficult State to analyze because there was no uniform data collection until the very end of the project at which time data for only 9 people were collected. There is uncertainty at the state level as to the future of the COMPASS project. From the data collected during this project for 28 individuals using the NY outcome assessment, it is clear there are problems in terms of reliability and validity. If the state decides to go forward with the development of an instrument, it is critical that attention be paid to establishing a reliable and valid instrument.



# OKLAHOMA REPORT

## Introduction

The Oklahoma site visit took place on November 7 through November 9, 1995. The kickoff meeting was held at the State of Oklahoma Developmental Disabilities Services Division (DDSD) in Oklahoma City. Project staff from Temple University's Institute on Disabilities (IOD) and from HSRI met first with the Division Director, James Nicholson, and then with the executive staff. IOD and HSRI staff gave an overview of the project, and they presented an overview of the Quality Assurance system in Oklahoma and their perspective on it. The Quality Assurance system in Oklahoma has 3 parts: Performance Standards (using the AC standards) done by the state, Consumer Monitoring done by OK-AIM, and the OSU Developmental Disabilities Quality Assurance Project. Each will be addressed separately below.

## Overview

Like many quality assurance systems, the Oklahoma system originated from a lawsuit (Homeward Bound, Inc. v. Hissom Memorial Center). The lawsuit was filed in 1985; a consent decree was issued in 1990. Due to the consent decree, the Homeward Bound Review Panel and the Homeward Bound Audit Team were formed. The Homeward Bound Audit Team does a sample of 50 people annually. There are 1059 Hissom class members, defined as people who lived at Hissom Memorial Center at the time of the lawsuit. Hissom Memorial Center closed in April 1994.

The residential system for people with developmental disabilities in Oklahoma consists of the following types:

- Public institutions (Enid, Paul's Valley, Greer Center) - 575 people

- Private ICF-MRs (about 20) - 2000 people (no state oversight)

- Supported living - 700 people

- Group homes - 675 people

- Foster care - 175 people

- Assisted living - 100 people



## **Description Of Data System**

Initial contact was made with the Program Administrator of the Quality Assurance Unit, Developmental Disabilities Services Division who is the contact person for all data requests. The AC Performance Standards data are available by agency. The Oklahoma AIM data are available by site. The OSU QA Project data are available by individual. The Quality Assurance Unit Program Administrator was informed of our data needs for this project, which are twofold:

- Comparative data on the 30 people on whom Health & Safety data were collected.
- A subset of variables on their entire data base.

The following is a brief description of the 3 parts of the Quality Assurance system.

### **Performance Standards (AC)**

The contact person for this part of the Quality Assurance System is the Program Administrator of the Quality Assurance Unit, Developmental Disabilities Services Division. The data base has state agency profiles of 4500 people monitored annually. Some of the variables available include: Performance Score Percentages, standards, citations, and contract citations. The state AC survey team does look at Health and Safety issues, which may be useful for comparison with the Health & Safety data collected by the Study Team.

### **Consumer Monitoring (OK-AIM)**

The contact person for this part of the Quality Assurance System is the coordinator of the Oklahoma AIM project. The project is about 3 years old, and monitors about 500 people per year. Data are site specific. This is a community consumer monitoring; data are not collected at the large state facilities. The consumer monitoring results in monthly feedback to staff. The Oklahoma AIM data is only now in the process of being computerized. For this reason, they were not visited.

### **Oklahoma State University Developmental Disabilities Quality Assurance Project**

The contact person for this part of the Quality Assurance System is Patricia Bell, Department of Sociology, Oklahoma State University, Stillwater, OK 73125. Other people interviewed at OSU: ~~Amanda~~ Fullerton, Barbara Murray, and Dick Dodder.

The project annually monitors about 3700 individuals who receive services from or through DDS; this includes all Hissom class members, all OBRA placements, and people receiving services under the HCB Medicaid Waiver. The project has been in place since 1990. The assessment instrument has 3 parts:

- an interview with the primary caregiver for an individual: adaptive and challenging behavior, integrative activities, medical needs and services, need for adaptive equipment, IHP, services and supports
- a consumer satisfaction interview: satisfaction with residential living arrangement, services, and interactions
- a qualitative site assessment: subjective assessment of how pleasant, comfortable, attractive, and safe the residential site is

The Oklahoma State University (OSU) Developmental Disabilities Quality Assurance (DDQA) Project was precipitated by the Homeward Bound v. Hissom Memorial Center lawsuit. A Request For Proposals was let by the Developmental Disabilities Services Division of the Department of Human Services. A successful proposal was submitted by Oklahoma State University. The project brought in James Conroy and Celia Feinstein, Quality Assurance consultants from Pennsylvania, who created the original data collection instruments and did the initial training of data collectors.

Since the inception of the project, the data collection instruments have been updated annually. The "Flag" form, which identifies important areas which may require immediate action by the provider of service, has been cut down to 4 items. In the past year, much work has been done by the project to improve the response rate of the consumer satisfaction interview. The original consumer interview data collection instrument has been converted into a picture book, which has been undergoing analysis of its validity and reliability.

Consequently, data collector training has been expanded to a 3-day training. It covers the history of the project, the policy and procedures manual, data collector ethics and terms, the instruments, people first language, disability awareness, the use of sign language, and consumer interview techniques. Using the resources available at the university, half of the data collectors are graduate students; the other half are human service professionals.

The project has experienced difficulty with the Human Subjects Review Board at the university. For this reason, they can only give their data to their contractor (State of Oklahoma, Department of Human Services, Developmental Disabilities Services



Division). All data requests go to the Program Administrator of the Quality Assurance Unit of DDSD.

Resources and reports obtained during the visit to OSU:

- DDQA Project Training Packet 1995-1996
- Fullerton, Douglass, & Dodder (1995). A Systematic Study Examining Reliability of Quality Assurance Measures.
- Conroy & Ervin (1992). Longitudinal Assessment of Consumer Outcomes: Measuring Changes in Independence, Productivity, and Satisfaction.
- Murray (1994). Measuring Changes in Consumer Outcomes: A Five Year Longitudinal Analysis. 1994 Yearly Report.
- Howard, Fouquet, & Dodder (1994). Measuring Consumer Satisfaction with an Adaptive Communication Device: A Test of Validity. Oklahoma State University.
- 1995 Data Management Plan.

## **Reliability**

There have been multiple reliability studies done on the OSU DDQA Project data. A preliminary study was conducted in Oklahoma in 1992 to determine inter-rater reliability of the scaled items for which interviews were conducted twice for a subsample of 86 (i.e. 2%) DDSD consumers. The range of the correlation is from -1 to +1. A correlation coefficient of +1 indicates that the scale scores were the same each time the assessment was conducted. Table 1 below summarizes the findings on the correlation coefficients.



### **Oklahoma: Reliability Correlation Coefficients on Scaled Items**

<b>Scaled Item</b>	<b>Correlation</b>
Behavior Development Scale	.93
Challenging Behavior Severity	.72
Challenging Behavior Frequency	.70
Consumer Satisfaction	.66
Physical Quality Scale	.05
Site Impression	.01
Social Interactions	.52

A coefficient of .4 and below was considered low, a score of .4 to .7 was considered moderate, and a score above .7 was considered high. As shown in the above table, the findings were high reliability for the Behavior Development Scale (Adaptive Behavior) and Challenging Behavior Severity scale; moderate reliability for the Challenging Behavior Frequency scale, Consumer Satisfaction, and the Social Interactions; very low reliability was indicated on the scales on physical quality and site impression.

A second study on reliability was conducted in 1995 by the Department of Sociology, Oklahoma State University, by Amanda Fullerton, Mark Douglass, and Richard Dodder.

Since the beginning of the project, a more in-depth and formalized interviewer training was put in place by OSU. Approximately half of the interviewers were recruited from the graduate research assistants from the Sociology Department at Oklahoma State University. The other half was comprised of professional interviewers who worked full time on this research project. In both cases, the interviewers had worked on this case for an average length of two years with less than half new interviewers each year.

The training process for interviewers was as follows:

- The history and objective of the project were detailed at the workshop.
- The population being studied was specified in a "Disability Awareness" section in training materials.
- The interviewers were trained on sign language for the "Consumer Satisfaction" section of the instrument along with basic interviewing skills.

- A Survey Instruction Manual and a Codebook were distributed among the project staff.
- The directors of the project staff with the aid of experienced interviewers trained new interviewers on the meaning of each item, ways of interpreting the responses, and the entering of responses that can be computer scannable as documented by the Codebook.
- The new interviewers engaged in role-playing with experienced interviewers to highlight situations which would lead to incorrectly interpreted responses.
- A brief summary was presented to explain the data analyses process. The utilization of the data was explained as well.

The third-day training was conducted by speech pathology consultants who detailed the specific characteristics of this population with developmental disabilities and the interviewing techniques specific to this population. The interviewers were also trained on the Adaptive Communication Device (ACD) which is a tool developed by the project staff to facilitate communication during the Consumer Satisfaction section of the instrument.

New OSU interviewers were paired with experienced interviewers for a two week in-field training to observe interviewing styles in different types of placements. The experienced interviewers supervised the first in-field interviews conducted by the new interviewers. Finally, the Senior Research Analyst observed each interviewer before they began their interviewing without supervision.

This study was a four independent variable cross-classification. The variables are: a) verbal/nonverbal; b) test-retest/inter-rater; c) parent/other caregiver; d) mild to moderate/severe to profound retardation. There were 112 individuals in the sample with 16 cells with 7 subjects in each cell.

The scheduling secretary on the Developmental Disabilities Quality Assurance Project at Oklahoma State University designated each interviewer as the inter-rater (different interviewer) or test-retest (same interviewer). Based on scheduling needs, verbal ability and geographic region the interviewers were assigned to each other. Two interviews had to be completed within a 14-day period for each individual in the sample.

The project personnel contacted the sample population to ensure that the interviewers completed the assessment in person and to ensure that the interviewers adhered to the outlined procedures.



Overall, the study indicated high reliability. Scales measuring Adaptive Behavior, Social Integration, Productivity, and Consumer Interview all had reliability coefficients greater than .80. For the scales on challenging behavior, frequency and severity, a Pearson R of .73 and .70 were recorded, respectively.

The 1995 reliability coefficients for scales in the instrument were as follows:

#### Demographics

Sex	.98
Race	1.0
Date of Birth	.96
Class Status	.87
Functioning Level	.79

#### Scales

Adaptive behavior	.99
Challenging behavior (frequency)	.73
Challenging behavior (severity)	.70
Consumer interview	.83
Social Integration	.89
Productivity	.85

In 1995, reliability was done on individual data only.

In summary, based on the 1992 and 1995 reliability studies done in Oklahoma, the scales used for the OSU Quality Assurance Project are highly reliable. The reliability tests done already by OSU are sufficient. There is no need for further reliability testing of the Oklahoma data.

### **Concurrent Validity**

The Adaptive Behavior, Challenging Behavior, Consumer Interview, and Social Integration scales used in Oklahoma are identical to the scales currently used in Pennsylvania. A concurrent validity analysis would be redundant. For this reason, a concurrent validity analysis does not need to be done.

### **Applicability**

The OSU Quality Assurance system has been used in a variety of settings. The project annually collects data in sites ranging from Assisted Living settings to HCB Waiver settings to Group Homes to Public Institutions. They collect data on individuals who



have a wide range of disabilities. For this reason, it is obvious that the QA system is applicable to a variety of settings.

## **Discriminant Validity**

OSU Longitudinal Assessment data were requested from the Quality Assurance Unit of DDSD. Through a consultant working on the project a random sample of 300 individuals was selected and forwarded to Temple University for analysis. These data have been received and have been analyzed by Temple staff to determine the discriminant validity of the instrument. The data were collected in 1995.

In order to assess the discriminant validity of the instrument, a discriminant function analysis was performed. The purpose of discriminant function analysis is to statistically distinguish between two or more groups. To distinguish between groups a collection of discriminating variables are selected, that measure characteristics on which the groups are expected to differ. Based on discussions among the Study Team, it was decided that the two variables to be used as discriminating variables would be level of disability (mental retardation) and living arrangement. The extent to which differences on the OSU instrument's scales can be explained by the discriminating variables was assessed. The outcome indices that were examined for purposes of this part of the study included:

- Number of outside events during the past week (inclusion);
- Adaptive Behavior;
- Consumer Interview;
- Challenging Behavior Frequency;
- Challenging Behavior Severity; and
- Number of hours of work or education per month.

For each of these indices, a discriminant function analysis was performed using the discriminating variables of level of mental retardation and living arrangement, to see whether group membership (for both level of mental retardation and type of living arrangement) discriminated scores on the five outcome scales. For purposes of this study, the living arrangement variable was collapsed from the original 18 categories to three categories which are: **group home**, including group home 4-6 people and group home more than 7 people; **foster/individual setting**, foster care, independent living and adult companion; and, **assisted or supported living**. Interestingly, in the random

sample selection, no one living in congregate care settings was selected. For purposes of this analysis the breakdown of the sample by type of setting is as follows:

Type of Setting	Frequency	Percent
Group Home	138	46%
Foster/Individual Setting	40	13%
Assisted or Supported Living	122	40%
Total	300	

Level of mental retardation for the group is as follows:

Level of Mental Retardation	Frequency	Percent
Not Retarded/Mild	121	40%
Moderate	69	23%
Severe	41	14%
Profound	53	18%
Unknown	16	5%
Total	300	

The first set of analyses examined the extent to which type of living arrangement was successful in discriminating between scores on the outcome measures. One of the ways to interpret a discriminant function analysis is that once a set of variables is found which provides satisfactory discrimination for cases with known group memberships, a set of classification functions can be derived which will permit the classification of new cases with unknown memberships. For example, if the scores on a given outcome variable are known, if the discriminating variables work well, one should be able to determine from which type of living arrangement the individual came as well as their level of mental retardation based on their outcome data. As a check of the adequacy of the discriminant functions, the original set of cases can be classified to see how many are correctly classified by the variables being used. The table below lists, by outcome measure, the percent of cases correctly classified using type of placement as a discriminating variable.

Percent of Cases Correctly Classified  
Using Type of Living Arrangement



# of Events Outside the Home	33.45%
During the Past Week	
Adaptive Behavior	45.42%
Consumer Satisfaction	27.94%
Challenging Behavior Frequency	44.67%
Challenging Behavior Severity	44.00%
Hours of Work/Education/Month	40.16%

In a variable such as living arrangement where there are three possible categories, one would expect to correctly predict group membership 33% of the time by chance alone. As the table above demonstrates, on each of the outcome variables with the exception of consumer satisfaction, we were able to predict outcome scores by living arrangement slightly more often than would be expected by chance alone. One of the problems with the sample selected, is that there is less variance in terms of living arrangement than in the population, as is demonstrated by the fact that no one living in congregate care settings was included in the sample.

The second set of analyses examined the discriminating properties of the variable, level of mental retardation. The table below lists, by outcome measure, the percent of cases correctly classified using level of mental retardation as a discriminating variable.

Percent of Cases Correctly Classified  
Using Level of Mental Retardation

# of Events Outside the Home	33.45%
During the Past Week	
Adaptive Behavior	64.18%
Consumer Satisfaction	39.38%
Challenging Behavior Frequency	26.06%
Challenging Behavior Severity	24.65%
Hours of Work/Education/Month	18.30%

In a variable with four categories, one would expect correct classification by chance alone in 25% of the cases. As the table demonstrates, and as one might expect, with level of mental retardation as the discriminating variable, adaptive behavior is correctly classified 64% of the time. Because of the correlation between the two measures, this is not surprising. For social integration and consumer satisfaction, classification is somewhat better than by chance alone. Challenging behavior frequency and severity and hours of work/education are predicted no better than by chance alone. Again, because the type of living arrangement in the sample is restricted to community living,



there is less variation in the group; people with the most severe disabilities are underrepresented in the sample.

In summary, the discriminant validity of the OSU instrument is better than would be expected by chance alone, for both type of living arrangement and level of mental retardation.

## **Health & Safety**

Part of the reason for the site visit to Oklahoma was to collect Health & Safety assessments. Health and Safety data were collected for 30 people. Residential placement types visited included: a public institution, a private ICF-MR, and several group homes. The purpose of this data collection was to examine the congruence between the health and safety data collected, the Oklahoma outcome measures, and other measures of health and safety. The other measures of health and safety collected in Oklahoma include the Quality Assurance Performance Surveys and the number of contract deficiencies using the DDS contract requirements. DDS QA staff conduct annual performance surveys in all ICFs/MR and in community residential arrangements. If a provider reaches 75% compliance with the standards they receive a certificate of achievement; 85%, they receive a certificate of excellence and a waiver of the next year's review. In terms of contract deficiencies, the number of deficiencies is reported by agency. In both of these efforts, agency, rather than individual scores are obtained. A table of the health and safety data by site is included.

These scores as well as the Temple University Health and Safety scores and the OSU Longitudinal Assessment scores were entered onto a mainframe computer and a Spearman correlation was performed to examine the relationships between the variables. Because many of the indices are site specific (QA Performance Surveys and contract deficiencies) the analyses were restricted to only four sites (the public ICF/MR, private ICF/MR and HCB-funded group homes). As a result, there were no significant correlations found between the outcome data and the various other health and safety and quality assurance mechanisms.

Address	O1	O2	O3	ACP	CONT	% MED	MEEND	%DOC	UI	BP	SAFE	ESC	SAFE	QAMED	%DOC	SI	AB	CBF	CBS	CSAT
						0.53	0.30	19.4	0.60	0.00	0.00	0.20	2.75	3.2	5.2	70.8	92.2	94.6	85.2	
SITE #1				89.3	12	0.83	0.00	16.0	0.17	0.00	0.00	0.00	3.00	2.8	4.8	76.4	93.7	95.0	83.0	
SITE #2				94	19	0.33	0.33	32.0	0.00	0.00	0.00	1.00	2.70	4.7	6.2	90.2	96.9	99.3	88.6	
SITE #3				85.2	70	0.00	0.25	18.7	0.00	0.00	0.00	0.00	2.70	2.4	5.0	32.9	89.3	93.0	78.4	
SITE #4				91	8	1.50	0.67	11.5	2.80	0.00	0.00	0.00	2.75	5.0	5.7	87.2	95.3	95.3	96.0	

## Conclusions

Overall, the Quality Assurance system developed by DDSD is very impressive. Data collection has been done on a large number of people (3700 per year) over a long period of time (5 years) in a variety of residential settings. Change over time can be measured on a statewide basis.

The outcome measures used in Oklahoma are reliable, based on several studies performed by Oklahoma State University. The scales used in Oklahoma were not analyzed for concurrent validity; they are identical to the scales used in Pennsylvania for comparison. The Quality Assurance system is used in residential settings ranging from public institutions to assisted living sites, and includes individuals ranging from people with mild disabilities to people with severe, multiple disabilities. The data are used to improve services to individuals. The discriminant validity demonstrates that outcomes can be predicted better than would be expected by chance alone when using the discriminating variables of type of living arrangement and level of mental retardation. Health and Safety data appear not to be correlated with the outcome data, however, this should be interpreted with caution, as the number of observations is small and the variance across variables is small.

## OREGON REPORT

The Oregon site visit was conducted on October 24-26, 1995. Individuals interviewed included: Mary Lee Fay and Sean McMullen of the Oregon Office of Developmental Disability Services (ODDS) and Rob Horner, Steve Newton and William Ard of the Specialized Training Program at the University of Oregon. The University of Oregon was involved in the development of Oregon's outcome monitoring system and currently is under contract to ODDS to perform data analysis, training and technical assistance along with the Oregon Technical Assistance Center (OTAC).

### Overview

The Residential Outcome System (ROS) was developed to support the shift from a program-focused system of assuring quality, to more person-centered measures. In the mid 1980's, the Neighborhood Living Project in the Specialized Training Program at the University of Oregon developed the Valued Outcome Information System (VOIS), a system used to measure accurate information about the lifestyles of individuals supported by ODDS. VOIS was approved by the ODDS for use in residential programs licensed to provide 24-hour residential support services. In response to requests for a more streamlined system for programs that served larger numbers of individuals, the Oregon Residential Lifestyle Information System (ORLIS) was developed in the late 1980's. In 1993, the VOIS/ORLIS system was revised into one system, with input from Oregon's residential programs, the Neighborhood Living Project, the Oregon Technical Assistance Corporation, and the Office of Developmental Disability Services. The underlying assumption of ROS is that the purpose of residential services is to help individuals achieve a high quality lifestyle in which there is a match between the individual's support needs and the support the individual receives, as well as a match between the individual's lifestyle preferences and the lifestyle the person actually needs.

The "valued outcomes" that are included in the ROS are:

- Physical integration;
- Social integration;
- Independence;
- Activity preference; and
- Activity variety.



The ROS is premised upon the completion of an Activities Catalog, a listing that includes both leisure and personal management activities. The overarching principle upon which ROS operates is that there must be consistency between assessment, program development and evaluation strategies. ROS provides such consistency by having the Activities Catalog provide the basis for assessment, program development and evaluation.

According to the researchers at the University of Oregon, one of the most critical factors in any evaluation system is that it provide immediate feedback to front-line staff. Within two weeks of sending in their data, staff are provided with a summary of the data. This reinforces staff in a way that encourages them to use the data and keep collecting it.

Initially, training in the use of the ROS was provided by the Oregon Technical Assistance Center. Currently, the providers are taking responsibility for training their own staff in the use of ROS. Interestingly, while project staff were in Oregon, a classified ad was seen for direct care staff that specifically stated, "experience with VOIS/ORLIS preferred."

## **Description Of Data System**

Through a contract with the Oregon Office of Developmental Disability Services (ODDS), ROS data are maintained by the Neighborhood Living Project of the Specialized Training Program at the University of Oregon. Residential providers collect ROS data on a quarterly basis and it is forwarded to the University of Oregon for analysis and reporting. The Research and Evaluation Unit of the Specialized Training Program produce a report every six months. The data collection process has been streamlined, such that direct contact staff are no longer responsible for graphing the data. Therefore, when asked how staff feel about the ROS, most staff report that it is a much improved system.

## **Reliability**

A study of Oregon's outcome assessments was conducted by J. Stephen Newton and Robert H. Horner of the University of Oregon. Eighteen programs with 24-hour staff participated. Programs were divided into four cohorts based on geographical clustering. Cohort A consisted of four programs; Cohort B consisted of 6 programs; Cohort C consisted of four programs; and Cohort D consisted of four programs. Three of the four programs in Cohort D were apartment-based as opposed to being group homes. All the programs in the

study had shift-type staffing. Thirty-three participants were randomly selected with 1 or 2 from each program. Consent was obtained from parents/guardians/advocates.

The four major dependent variables in the study were:

- a) physical integration;
- b) social integration;
- c) social network size; and
- d) social network structure.

Physical Integration is defined as: participation in activities beyond the boundaries of the homes of individuals with disabilities; the average length of each activity was at least 15 minutes; and the activities involved integration of skills which had utility at home or in community life. Examples of such activities are grocery shopping, playing basketball, etc.

The Resident Lifestyle Inventory (RLI) was one of the techniques employed to measure physical integration. The RLI was used to interview two people from the staff of the residential program who were well-versed with the participants' daily activities. The RLI lists 144 activities. The interviewer noted: a) the frequency of each activity in the last 30 days; and b) whether those activities were performed at home or in the community.

Physical integration was also measured by direct observation of the participants' activities with the utilization of the "Valued Outcomes Information System" or VOIS. A staff member completed an "Activity Tag" for each participant. The tag recorded the name of those with whom the activity was performed; the name of the activity itself; and an indication of the physically integrated nature of the activity. The VOIS recorded the activities weekly.

The second variable used for the analysis was Social Integration, which was operationalized as involvement in an activity with individuals outside the program excluding the residential staff and other participants of the residential program. The first measure was taken from the Social Network Analysis Form (SNAF) which required the participants to name all individuals they considered as "socially important" within their a) family; b) co-workers, schoolmates, other residents; c) people paid to provide service; d) friends; and e) neighbors/others.



For each person named, the respondent was asked the number of activities they had performed with them in the last thirty days.

The second measure was obtained from the VOIS Activity Tags which produced the number of activities experienced each week by the participants, including those in the home.

Reliability and validity of the data were assessed using the following:

**VOIS:** Approximately 175 staff members produced activity tags from the 18 participating programs. A VOIS workshop was conducted to train the staff on coding of the activity tags. The staff scored 85% higher following the training. An inter observer tagging accuracy was obtained from 6 geographically convenient programs. One coder from each of the 6 groups with a score of 95% and above was designated the "master coder". The master coder, with other staff members, collected 20 tags: a) unobtrusively with at least 80% of the program staff; b) within a 4-week period; and c) included at least 5 activities which occurred within the community. In total, 280 tags were completed across the 6 reliability programs.

The first level at which the inter observer agreement determined the reliability of the question was related to the level of agreement among the independent observers with respect to the occurrence of physically and socially integrated activities. Within a range of 85%-100%, a 97.44% agreement was reached on whether or not a socially or physically integrated activity had occurred. The agreement level was 99.24% with respect to agreement on the physically integrated activity within a range of 99.44%-100%. Within a range of 94.12-100%, the average for agreement on socially integrated activity was 98.84%.

The study demonstrated the inter-rater reliability of the instruments used. However, there are certain limitations of this study. Because the programs were not randomly selected, the external validity of the study is questionable. Nevertheless, this limitation is partially minimized given that Oregon has implemented the VOIS feedback system in approximately 200 programs over the past years indicating positive results.

The findings are limited by a lack of a continuous direct observation by unbiased research staff with regard to interviews. Nevertheless, the study does support previous findings indicating positive results of the implementation of the feedback system irrespective of the limitations of the present study.



## **Concurrent Validity**

Concurrent validity has been established between the VOIS and several other instruments that measure valued outcomes for individuals. The instruments that were used to establish concurrent validity with the VOIS include the Behavior Development Survey (one of the instruments being used for concurrent validity measures in this project), and the Lifestyle Map (O'Brien). The concurrent validity study was completed by J. Stephen Newton at the University of Oregon (1986).

In terms of the Lifestyle Maps, statistical analyses revealed medium to large positive correlations between ratings on the Lifestyle Maps and the measures on the VOIS instrument, validating the measures of social and physical integration. The correlation between physical integration and the Community Presence Map was .42 and the correlation between the Community Participation Map and social integration was .47.

With regard to the Behavior Development Survey, statistically significant correlations were obtained between the VOIS measure of social integration and the BDS factors of Personal Self-Sufficiency (.52), Community Self-Sufficiency (.47), Personal Social Responsibility (.49) and Personal Adjustment (.56).

## **Applicability**

The ROS is currently used in community programs in Oregon. Although some components have been adopted for use at Fairview, one of the state's large ICFs/MR, the ROS in its entirety is not being implemented in any large setting. However, this observer did see the ROS being implemented in a state-operated group home for people with significant medical needs.

Because of the intensity of the ROS and the ongoing nature of the data collection effort, it was determined that bringing it to Pennsylvania to examine its applicability across settings was not feasible. In order to perform such an exercise, the administration and staff of a large setting would have to be invested in the process. Strictly for scientific inquiry, it would be virtually impossible to gain the cooperation of the administration. As a result, it is questionable as to whether this instrument could be used in a large facility without significant support to staff to maintain the level of effort required to effectively utilize the system.

## **Discriminant Validity**

The Oregon Office of Developmental Disability Services was contacted to request ROS data to perform the discriminant validity portion of the study. ODDS approved the release of the data, and a file was electronically transmitted to Temple from the Neighborhood Living Project at the University of Oregon. The data file include 970 individuals. Unfortunately, the data did not include an acceptable pool of "discriminating variables" such as type of living arrangement or level of disability. The data file that was transmitted, due to concerns about confidentiality, did not have identifying information which would allow us to "match" the outcome data with our data. In a similar vein, there were no demographic data in the ROS data set. Therefore, it was impossible to perform a discriminant validity analysis.

## **Health And Safety**

During the site visit to Oregon, 31 forms were collected using the Temple University Health and Safety Assessment developed by the Temple IOD. Because the ROS is only used consistently in community settings, all data were collected in community settings in the Eugene, Salem and Portland areas. The intent was to compare data from the Health and Safety surveys to ROS data as well as to ODDS licensing data. Because the ROS forwarded to Temple by the University of Oregon data not have identifying information even at the provider agency level, it was impossible to use the data for Health and Safety comparisons. Because there are no ICFs/MR in the community, comparisons were not made with ICF/MR data.

The ODDS licensing data were forwarded to Temple for inclusion in the Health and Safety analysis. The plans of correction were included for each licensing review and were used as a source of data for this analysis. Numbers of deficiencies were counted in the health and safety area as well as in other areas. Deficiencies were coded into three areas: 1) must be corrected immediately; 2) must be corrected within 30 days; 3) must be corrected in 90 days or at a time assigned by the agency self-assessment team.

In order to analyze these data, a correlation matrix was produced, using the Spearman Correlation procedure, a non-parametric test. Some of the licensing items were correlated with the data collected by Temple. The number of unusual incidents was negatively correlated with health and safety deficiencies requiring immediate correction, health and safety deficiencies requiring



correction within 30 days, and other deficiencies requiring immediate correction. None of the other variables was significantly correlated.

ADDRESS	#MED 0.55	MEDND 0.81	#DOC 12	UI 0.4	BP 0	SAFS 0.2	SAF 0.58	OD1	OD2	OD3-4	HSD1	HSD2	HSD3-4
SITE #1	2	1	24	0	0	0	1	12	6	1	5	5	0
SITE #2	0.25	0.25	11	0.3	0	0.3	0	11	7	6	6	3	6
SITE #3	1.4	0.8	22	0.8	0	0	0	2	1	3	1	0	1
SITE #4	0	1	5	0.8	0	0.4	1	7	0	0	5	0	0
SITE #5	0.67	3	9	0	0	0.3	1	6	1	0	6	1	0
SITE #6	1.5	0.5	19	2	0.5	0.5	2	2	0	0	2	0	0
SITE #7	0	0.75	13	0	0	0	1	11	5	0	7	1	0
SITE #8	0	0	4.7	0	0	0	0	18	4	0	14	1	0

## Conclusions

The new version of the ROS presents a more parsimonious model for collecting data than was provided by its predecessors (VOIS/ORLIS). The amount of data collection and analysis required of direct care staff is lessened, and they are, we believe, more likely to collect these data in a consistent and reliable way. Additionally, from talking with staff, it is obvious that the data are used in program development on an ongoing basis. The ROS is demonstrated to be a reliable instrument and is concurrently valid with other instruments in the field used to measure quality outcomes for individuals with developmental disabilities.

There are, however, several downsides to the ROS. Many interviewees continue to complain about the overly quantitative nature of the assessments. In addition, there is no linkage between the ROS data and licensing survey data. As succinctly stated by one respondent, "ROS was created to promote quality, licensing exists only to prevent atrocities." While some may view this as a problem with the instrument, as the data in other states has demonstrated, the issues of health and safety may be quite different and distinct from those related to quality outcomes.





## UTAH REPORT

The Utah site visit took place November 27-29, 1995. Individuals interviewed included: George Kelner, Sue Geary, Sue Marquardt, Georgia Baddley, Renae Taylor, Robyn Mendenhall, Nonie Lancaster, Sylvia Wright, Sharon Yearsley from the Utah Division of Services for People with Disabilities, Alan Hayward of the Office of Licensing Human Service Programs within the Department of Human Services, Ann E. Lee, Tracey Freeman and Helene Middleton from the Department of Health and David Hennessey, a provider who was instrumental in the development of a consumer survey.

### Overview

In 1990, the Department of Human Services in Utah regionalized. This shift in responsibilities and operation of services and programs for people with developmental disabilities resulted in the need for the Division of Services for People with Disabilities (DSPD) to refocus its quality assurance activities. After a review and analysis by HSRI, it was recommended that the Division get out of the business of licensing and focus its energies on review and support, technical assistance and training. A Quality Assurance Academy was convened consisting of individuals representing consumers, parents, provider and advocacy organizations, state legislators, case managers, Office of Social Services contract managers and regional and DSPD managers. The Academy recommended that the service system to people with disabilities be driven by the principles of informed choice, community membership/citizenship and individualization.

In response to the recommendations of the Academy DSPD developed an Outcomes Survey. The Outcomes Survey is comprised of the following four standards:

1. The provider makes available for the individual served opportunities for personal growth and development in an environment which uses the least restrictive alternatives available which are compatible with the needs, choices and goals of the individual.
2. The provider facilitates program individualization through full participation of the individual in planning and implementation of the IPP and training to allow for informed decision and choice making.
3. The provider enables the individual to fully participate in Utah life and practice a normal lifestyle through providing opportunities for the individual to live, work and associate with other people, including those

with and without disabilities, using services readily available (generic) in the community.

4. The provider has a quality assurance system in place which assures that services are provided to individuals as required by the policies and procedures of the Department of Human Services, Division of Services for People with Disabilities, and the Title XIX Home and Community Based Waiver; which meet the Department of Human Services Licensing or Certification Standards, Division of Services for People with Disabilities standards, and all the Office of Social Services Contracting requirements as detailed in the Attachment E of the Office of Social Services' contracts.

The first three standards are comprised of 10 items each. Each item is rated on a scale of one through six, with the following elements considered in the rating of each of the items: method of assessing interest and skills; evidence of opportunities for information; evidence of education and training; interagency coordination; participation; and quality. The fourth standard is simply rated pass or fail. The total possible score for each standard is 60. In order to receive a passing score, the total score for each of the first three standards must be at least 63% of the possible points, or a score of 38.

If an agency does not meet criteria on one of the standards, a plan of correction is required; a follow-up survey is then performed to determine whether the plan of correction has been implemented.

The Outcome Surveys are completed by staff of the Quality Assurance Unit of DSPD. The instrument was developed by the unit and training in administration of the survey is conducted on-site in most cases. Two-hour training sessions are also held periodically. Case managers participate in the Outcome Surveys as part of their own training.

The Outcome Surveys are performed for individuals living in community programs that are funded through the Home and Community Based Waiver and those individuals in 100% state-funded placements. However, for the most capable individuals, (as identified by scores on the Instrument for Client and Agency Planning (ICAP) of Level 1 or 2) Outcome Surveys are not completed. A consumer satisfaction survey is completed and if the individual reports dissatisfaction, an Outcome Survey is then completed. In each year a 3% random sample is drawn, including at least one individual from each provider agency.

In addition to the Outcomes Survey, DSPD has had a consumer survey developed which is administered to 10% of the individuals receiving supported



living services. These data are reported in narrative form and are not amenable to quantitative analysis. DSPD also sponsors a volunteer monitoring component in which DSPD staff train the monitors, meet regularly with the leaders of the monitoring group and address concerns raised during volunteer monitoring visits.

## **Description Of The Data System**

The Outcomes Survey data are maintained by the Quality Assurance Unit of DSPD. Reports are generated on an annual basis analyzing the standards by type of program, ICAP functioning level and by region. Raw scores are entered into a data base program on a microcomputer.

## **Reliability**

Reliability data are collected each year and are examined and utilized to target further training for the surveyors. In the reliability studies, two raters complete scores for an agency, with one rater does the actual interviewing, the other observing. In the most recent report in which data were reported, inter-rater reliability scores ranged from 19% to 78%. This presents cause for some concern. DSPD identified one surveyor as having particularly low scores and that individual has been given additional training and opportunities for practice reviews. The results of the reliability study are presented each year as part of the annual report. Because of the length of the outcome survey process, and the requirement for intensive training in the application of standards, it was determined that a reliability study by the project was not feasible.

## **Concurrent Validity**

The Division took the Outcomes Survey to the State of Colorado and administered the survey in six sites. In five of the six sites the same individuals were residing in the sites as when the Colorado surveyors performed their own surveys. The Utah surveyors rated the programs on a Likert scale of best to worst and had a 100% agreement with the Colorado surveyors' results on their instruments. Unfortunately these data have not been reported formally. Again, because of the length of the outcome survey process and the requirement for intensive training, it was determined that further study of the concurrent validity of the Utah instrument was not feasible.



## Applicability

The Utah instrument has been used only in HCBW settings and in settings that are 100% state funded. The survey is not used in private or public ICF/MR facilities. Neither is the survey used in settings supporting individuals with the highest ICAP scores, i.e., individuals who are the most capable, as it is seen as unnecessarily obtrusive. Given the length of the survey and the need for extensive training, it is not feasible to administer the survey in Pennsylvania. The outcome survey is utilized, however, in settings supporting people with significant disabilities, people who use wheelchairs, and people with significant communication disabilities. It has been reported by Q.A. Unit staff, however, that the instrument could possibly be used in ICFs/MR with some additional training of staff. The major reason that the process has not been used in the ICF/MR program is that DSPD does not have jurisdiction over the ICFs/MR; rather they are under the auspices of the Department of Health.

## Discriminant Validity

This portion of the review determines the extent to which the Outcomes Survey can successfully discriminate between individuals based on their scores. An example would be whether, based on Outcomes Survey scores, residential settings can be predicted. In order to analyze the discriminant validity of the instrument the most recent Outcomes Survey data have been forwarded to Temple, and the analysis have been performed. Although scores are attributed to agencies, the raw data for individuals is entered onto the microcomputer. The data file forwarded to Temple for analysis included data for 84 individuals.

In order to assess the discriminant validity of the instrument, a discriminant function analysis was performed. The purpose of discriminant function analysis is to statistically distinguish between two or more groups. To distinguish between groups a collection of discriminating variables are selected, that measure characteristics on which the groups are expected to differ. Based on discussions among the Study Team, it was decided that the two variables to be used as discriminating variables would be level of disability (in this case the Instrument for Client and Agency Planning (ICAP)) and living arrangement. The extent to which differences on the outcome instrument's scales can be explained by the discriminating variables was assessed. The outcome indices that were examined for purposes of this part of the study included:

- Opportunities for personal growth and development;
- Program individualization through participation in the ISP;



- Opportunities for community inclusion; and

The final outcome, existence of a quality assurance system was not included, as it is not a scale; rather it is a dichotomous variable. For each of these indices, a discriminant function analysis was performed using the discriminating variables of ICAP level and living arrangement, to see whether group membership (for both ICAP level and type of living arrangement) discriminated scores on the five outcome scales. For purposes of this study, the living arrangement variable includes: **day training, group home, professional parent, supervised apartment and employed.** For purposes of this analysis the breakdown of the sample by type of setting is as follows:

Type of Setting	Frequency	Percent
Day Training	30	36%
Group Home	14	17%
Professional Parent	10	12%
Supervised Apartment	25	30%
Employed	5	6%
Total	84	

ICAP level for the group is as follows:

ICAP Level	Frequency	Percent
1	6	8%
2	16	21%
3	13	17%
4	5	6%
5	37	48%
MISSING	5	
TOTAL	84	

The first set of analyses examined the extent to which type of living arrangement was successful in discriminating between scores on the outcome measures. One of the ways to interpret a discriminant function analysis is that once a set of variables is found which provides satisfactory discrimination for cases with known group memberships, a set of classification functions can be derived which will permit the classification of new cases with unknown memberships. For example, if the scores on a given outcome variable are known, if the

discriminating variables work well, one should be able to determine from which type of living arrangement the individual came as well as their ICAP level based on their outcome data. As a check of the adequacy of the discriminant functions, the original set of cases can be classified to see how many are correctly classified by the variables being used. The table below lists, by outcome measure, the percent of cases correctly classified using type of placement as a discriminating variable.

Percent of Cases Correctly Classified  
Using Type of Living Arrangement

Opportunities for personal growth and development	42.86%
Program individualization through participation in the ISP	42.86%
Opportunities for community inclusion	26.19%

In a variable such as living arrangement where there are five possible categories, one would expect to correctly predict group membership 20% of the time by chance alone. As the table above demonstrates, on each of the outcome variables, we were able to predict outcome scores by living arrangement more often than would be expected by chance alone.

For the first two standards, prediction of group membership is twice as good as would be expected by chance alone. For the third standard, opportunities for community inclusion, prediction of group membership was slightly better than by chance alone.

The second set of analyses examined the discriminating properties of the variable, ICAP level. The table below lists, by outcome measure, the percent of cases correctly classified using ICAP level as a discriminating variable.

Percent of Cases Correctly Classified  
Using Level of Mental Retardation

Opportunities for personal growth and development	29.87%
Program individualization through participation in the ISP	37.66%
Opportunities for community inclusion	26.19%

Again, in a variable with five categories, one would expect correct classification by chance alone in 20% of the cases. As the table demonstrates, the outcome

scores correctly predict group membership by ICAP level more often than would be expected by chance alone, for all three outcome indices.

In summary, the discriminant validity of the Utah outcome instrument is better than would be expected by chance alone, for both type of living arrangement and ICAP level.

## Health And Safety

Temple data collectors have completed health and safety assessments for 30 individuals in Utah; several of whom live in private ICFs/MR; the remaining individuals living in a variety of community programs. For the 30 individuals for whom data were collected, additional data were obtained from the DSPD as well as other offices involved in surveying health and safety issues, including the Department of Licensing within the Department of Human Services, and the Division of Medicaid program Certification in the Department of Health. For those individuals living in ICFs/MR, the only other health and safety data available is that produced through the ICF/MR survey in the form of an Onsite Survey and Certification Automated Reports (OSCAR). The OSCAR data includes the actual number of deficiencies in three areas: Conditions of Participation, Standards and Life Safety Code. In addition to providing data on actual number of deficiencies in each of the three areas, information is provided on how these data compare to the national average number of deficiencies. A scale was developed for each of the three areas, comparing the facility to the national average. The scale ranges from 1 to 5, where:

- 1 = Much worse than national average (more than 2 points);
- 2 = Somewhat worse than the national average (2 points or less);
- 3 = The same as the national average;
- 4 = Better than the national average (2 points or less); and
- 5 = Much better than the national average (more than 2 points).

Because the population of individuals living in ICFs/MR is not under the jurisdiction of DPSD, Outcome Surveys are not completed. The ICF/MR survey is the only quality assurance mechanism.

For those individuals living in smaller settings, there are several other health and safety mechanisms in place. For those settings where four or more



individuals live, a licensing survey is completed by the Division of Licensing within the Department of Human Services. Data were provided on the Residential Treatment Checklist and the Life Safety Checklist. In the case of each of the instruments, the total number of deficiencies was collected.

For individuals living in settings of fewer than four people, a Certification Checklist is utilized; on that instrument total number of deficiencies were recorded for each site. Once all of the data were collected, they were entered onto a spreadsheet and uploaded onto the mainframe computer at Temple for analysis. To simplify the analysis, the residential checklist, certification checklist and life safety checklist were combined to form one variable called licensing. On that variable, actual number of deficiencies were reported. Because the size of the sample was small (there were only 12 individuals for whom there was individual outcome data), non parametric statistics were used; in this case Spearman Correlations were computed for all of the Health and Safety data, along with the actual outcome scores on the first three indices mentioned above. Again, the existence of a quality assurance system (outcome 4) was not included, because it is a dichotomous variable and showed very little variance.

The analysis resulted in very few statistically significant correlations. The only outcome measure that was correlated, was the third outcome, opportunities for community inclusion, which was inversely related to the safety scale which included inadequate number of smoke detectors, no fire drill in the past 60 days, etc. ( $Rho = -.54$ ,  $p < .07$ ). The state health and safety item that was significantly correlated was the licensing item which included the number of deficiencies on any of the three licensing checklists. The licensing deficiency scale was inversely correlated with the number of doctor's visits ( $Rho = -.59$ ,  $p < .008$ ) and inversely correlated with the safety item ( $Rho = -.43$ ,  $p < .06$ ) which asks about neighborhood extremely unsafe neighborhood. This may be explained with the assumption that the less safe the neighborhood, the more likely the site was to have deficiencies on licensing surveys.

Address	O1	O2	O3	QA1	QA2	QA3	MED 0.87	MEDND 0.5	#DOC 8.9	UI 0	BP 0	SAFESC 0.83	SAFE 0.87	CERT	RES	LS
SITE #1				70	72	68	0	0	3	0	0	2	0		0	2
SITE #2				73	82	82	0	1	7	0	0	0	1		0	0
SITE #3				70	70	78	0	0	1	0	0	0	0		1	0
SITE #4				72	77	77	0	0	3	0	0	0	0		1	1
SITE #5				73	78	75	0	0	7	0	0	0	1	0		
SITE #6				77	83	75	0	2	7	0	0	0	0	0		
SITE #7				73	78	77	0	0	3	0	0	1	0			
SITE #8				50	58	57	0	0	9	0	0	1	1	0		
SITE #9				85	85	83	3	0	0	0	1	0	1	0		
SITE #10				85	85	82	0	0	8	0	0	0	0		0	0
SITE #11				67	67	68	1.5	0	15	0	0	0	1	0		
SITE #12				73	73	80	0	0.5	12.5	1	0	0	1	0		
SITE #13							0	1	4	0	0	2	0		0	0
SITE #14							1.5	0	6	0	0	0	2	0		
SITE #15							0	0	18	0	0	0	1	0		
SITE #16							4	1	0	0	0	0	1	1		
SITE #17							0	0	6	2	0	3	3	0		
SITE #18	4	4	2				1.8	0.8	9	0	0	1.2	1			
SITE #19	4	5	4				1.4	1	17	1	0	2	1			

## Conclusions

The Quality Outcomes Survey has been used in Utah for more than five years. The data collection has facilitated the delivery of technical assistance by DSPD and the data have been used as part of a "report card" that is produced by the Division each year. The survey reflects the vision and mission of DSPD. However, the Outcomes Survey is seen as cumbersome by many. Reviews are lengthy and given the sampling strategy, it is not clear that they are representative of an agency's performance. In addition, the Survey is only used in HCBW and state-funded settings, leaving out those individuals seen as most vulnerable as well as those individuals seen as most capable.

The outcome assessment instrument may be reliable, but should be subjected to a more formal reliability study as well as a concurrent validity study to give it more credibility in the field. Regarding health and safety, the outcomes assessment process does not seem to be related to health and safety in any major way. The separation of licensing and quality assurance functions, however, seems to be working quite well.





# WYOMING REPORT

## Introduction

The Wyoming site visit took place on November 30 through December 2, 1995. An initial meeting was held in Cheyenne between project staff and key State agency staff for the purpose of informing state personnel of the intent of the HCFA project as well as providing project staff with an overview of the quality assurance system for individuals with developmental disabilities. Temple University's Institute on Disabilities (IOD) staff met with the University of Wyoming /UAP staff to ascertain the availability of outcome measurement instruments. During the site visit IOD staff also collected health and safety information on 32 individuals receiving residential services from the Division of Developmental Disabilities (DDD) in Cheyenne, Riverton, and Lander. The following individuals were interviewed during the site visit:

- Robert Clabby, Division of Developmental Disabilities Administrator/Wyoming State Training School Superintendent
- Jon Fortune, Ed.D., DDD, Adult Services Manager
- Ken Heinlein, Ed.D., University of Wyoming/UAP
- Nancy Riley, DDD Resource Specialist, Cheyenne
- Sharon Kelsy, Magic City Enterprises, Cheyenne
- Ramona Doidge, DDD Resource Specialist, Riverton/Lander
- David Brunner, WSTS, Quality Assurance Coordinator
- Michael Aurand, WSTS QMRP
- Shawn Griffin, Community Entry Services (CES), Chief Operations Officer
- Joe Hoffman, CES Community Living Director

Contact with key stakeholders in Wyoming by IOD staff was continuous as systems for analysis of the health and safety data were developed and the need for securing additional information was identified.

## Overview

Wyoming is a vast, sparsely populated, rural state which has nine major community providers and one large state-run ICF/MR, Wyoming State Training School (WSTS). One hundred and forty one individuals reside in WSTS, with approximately 915 individuals being supported in the community. Of those being served in the community, 740 adults and children are supported through the HCB waiver. State officials are very proud of the fact that they have no community based ICF/MR programs.

In 1990, the Wyoming Protection and Advocacy System, Inc., filed a class action suit (Weston, et al. v. Wyoming State Training School, et. al.) against the state on behalf of all individuals with mental retardation, currently at the WSTS, and those individuals at risk of being placed at WSTS. A Consent Decree, negotiated in 1991 precipitated an accelerated rate of community placement for residents of WSTS; the establishment of an Independent Case Management system; and a requirement that the division draft quality assurance standards. The division has published a report outlining all quality assurance efforts in community services for persons with developmental disabilities and mental retardation since 1991. A Settlement Agreement replaced the Consent Decree in January 1995 maintaining the State's requirement for quality assurance efforts and Independent Case Management Services.

State legislation enacted in 1982 was initiated by community providers to require the Commission on Accreditation of Rehabilitation Facilities (CARF) to accredit community programs. As of the site visit date, all nine of the major community providers had attained three year accreditation status, (the longest period of time an agency can receive accreditation from CARF). The community providers are required under CARF standards to complete their own internal program reviews. No Wyoming agency is scheduled to undergo the new outcome based CARF accreditation process until 1997.

In addition to CARF accreditation, the Wyoming Division of Developmental Disabilities conducts an annual program review for each of the provider agencies. A team of four to six individuals from the DDD and the Governor's Planning Council on Developmental Disabilities review all aspects of an agency's programs, and issues a narrative report. Particular attention is given to any of the CARF standards in which an agency was deficient. The state review monitors the agency's action plan to correct the deficiency during their annual review.



Wyoming has been using the Inventory for Client and Agency Planning instrument (ICAP) (Bruininks, Hill, Weatherman, & Woodcock, 1986) to measure the adaptive behavior, functional characteristics and challenging behaviors of the individuals it provides supports to, since 1988. In 1994, **Coming Home on the Range: Changing ICAP Profiles of the People Served and Their Community and Institutional Services in Wyoming, 1988-1994** (Fortune, Heinlein, Martinez & Fortune) compared the statewide data set from 1988 to 1994. The study found an increase in the number of persons being supported in the community instead of the institution, "...164 individuals with a variety of disabilities, requiring different levels of support are now being served in the community programs instead of the state institution. There are also 116 people served in the community during that time who were diverted from institutional care." The research further demonstrated "that individuals with a wide range of needs can be served in community programs in a profoundly rural state if provided with a choice of well funded services that the people who are served need."

The Resident Lifestyle Inventory (RLI), is a survey instrument developed in Oregon to monitor the extent of an individual's participation in community activities. This instrument was administered to people receiving residential supports under the auspices of Wyoming's DDD for the month of July 1993. Independent Case Managers conducted interviews with class members and a knowledgeable informant. Information was collected about the array of activities class members (N=99) were engaged in during the 30 days prior to the interview. (Collecting the data retrospectively as Wyoming did differs from the RLI's use in Oregon. Information is collected using the RLI in Oregon as it is occurring, on a weekly basis). The Independent Case Managers also interviewed two staff members from each Regional Service Provider and from WSTS (N=21). The data gathered from these two groups was compared and different patterns of activities for each group did emerge. On average, staff engaged in more activities than class members. There are no plans to use this instrument again, as it was perceived to be too time consuming.

A Consumer Satisfaction Survey was conducted for three years, from 1992 to 1994, as mandated by the Consent Decree. The surveys were sent to primary contacts of a sample of adult class members and non class members. Responses were received in 1994 from 109 primary contacts. The questionnaire consisted of 30 questions asking the primary contact to rate the quality of services. The response rate for the two groups was different, "Class members had a 54% (61 of 113) response rate and non-class members had a 60% (48 of 80) response rate, when returns for incorrect addresses were taken into account. The effective response rate was 56.5%, which is about ten percent less than the 1993 survey,

but above the minimum response rate of 50% commonly regarded for valid results." (1994 Consumer Survey Results, Ken B. Heinlein, Ph. D.)

Wyoming's Protection and Advocacy Agency developed a 10 question survey instrument to be used for collecting information on Regional Service Providers. This instrument focuses primarily on the existence of agency policies and procedures for ensuring the rights of individuals receiving supports from the providers. The instrument also documents an agency's in-service training programs.

ARK Regional Services, a Wyoming regional provider has developed a copyrighted Outcome Management System called SEE. SEE is an acronym for Satisfaction, Effectiveness, and Efficiency. These principles are core requirements of the CARF accredited Outcome Management System. The system is available for use, free of charge, by Wyoming agencies. ARK Regional Services also plans to market their system nationally.

The University of Wyoming/UAP has designed a Quality of Life Questionnaire to gather data related to the DDD's identified outcomes. The UAP has submitted a proposal to the Division to collect data on a 15% sample of adults with developmental disabilities receiving HCB waiver services. Included in this proposal would be a modified version of the consumer satisfaction survey used in 1992 through 1994. This survey would be mailed to the primary contact person of the adults receiving HCB waiver supports. The UAP is hoping for FY '97 funding of this project.

## **Description Of The Data Base**

The following components of Wyoming's quality assurance system are available on various data bases and computer programs. ICAP information is available as an ASCII file. One month's data on the RLI is available on the SPSS system. Data from the Primary Contact survey is also available on SPSS. The State survey is available on a word processing file. The CARF data is not maintained on a computer program.



## **Reliability**

There is not one viable outcome measure instrument that is being used in Wyoming at this time, therefore, the Study Team has determined that a reliability study is virtually impossible to conduct.

## **Concurrent Validity**

There is not one viable outcome measure instrument that is being used in Wyoming at this time, therefore, the Study Team has determined that a study of concurrent validity is virtually impossible to conduct.

## **Applicability**

There is not one viable outcome measure instrument that is being used in Wyoming at this time, therefore, the Study Team has determined that we are unable to establish any properties of applicability.

## **Discriminant Validity**

There is not one viable outcome measure instrument that is being used in Wyoming at this time, therefore, the Study Team has determined that we are unable to determine any discriminant validity properties.

## **Health And Safety**

Health and Safety data were collected on 32 individuals residing in seven community residences and the Wyoming State Training School. Two regional provider agencies were represented in this sample. This information was collected in the state capital, Cheyenne, which is located in the southeastern portion of the State and toward the middle of this vast state in the Riverton/Lander area. The data were collected on November 30 and

December 1 and 2 by IOD staff using the Temple University Health and Safety Issues Instrument, developed by the Temple University Institute on Disabilities/UAP.



The health and safety data collected at WSTS was compared with OSCAR data. The community residence health and safety data collected with the Temple University Health and Safety instrument was compared with the CARF accreditation data completed for each agency in 1994 using the 1993 CARF standards. A further analysis of the health and safety data collected at the community sites was originally contemplated by the Study Team. Our intention was to compare the health and safety data with the findings contained in the state reports as part of their annual site review. The state site reviews are reported in narrative form that is not quantifiable. Therefore, because the licensing information is too qualitative in form, we are unable to analyze this information and compare it with the health and safety data.

The CARF Accreditation Site visits for the two agencies in Wyoming where HCFA health and safety data was collected were conducted by CARF using the 1993 CARF standards. These standards are not outcome measures but are used as part of a process system of accreditation. The results of the accreditation process results in accreditation of either 1, 2, or 3 years. Both agencies were accredited for 3 years. The CARF Survey Report is the document produced by the CARF Survey Team which is reported in narrative form and is organized by separate Organizational and Programmatic Sections; e.g. under the Specific Program Standards section the programs an agency provides are delineated and a narrative report citing particular standards are listed.

CARF uses four possible ratings for the 1993 standards. The ratings are Conformance with Commendation, Conformance, Conformance with Suggestion, and Non-Conformance with Recommendation. The following rating scale has been developed for the CARF ratings.

Conformance with Commendation =4

Conformance=3

Conformance with Suggestion=2

Non-Conformance with Recommendation=1

In order to conduct a comparison of the Temple University health and safety information and the ratings contained in the CARF Survey Report the Study Team identified 4 applicable sections in each of the agencies' CARF Survey Reports. These sections were identified as being applicable for analysis in that they contained criteria which could be matched under the eight HCFA outcomes. The CARF sections are Physical Facilities, Health & Safety;

**Assessment; Individual Plan Development, Implementation, and Management; and Community Living Programs: Integrated.**

In addition to identifying the total number of applicable standards in each of the four sections we applied the rating scale mentioned above to each section and established the range of scores possible that an agency could attain for each of the sections. The following table displays the identified sections; the number of applicable standards and the possible range of scores :

Applicable CARF Rpt.Sections	# of Standards	Range of scores
Physical Facilities, Health & Safety	8	8-32
Assessment	3	3-12
Individual Plan Development, Implementation, and Management	4	4-16
Community Living Programs: Integrated	12	12-48

In the analysis of the data we conducted non parametric correlations and assessed the Spearman Correlation Coefficients and found no significant correlations. This in part is due to the small number of cases in the study. In addition, it is possible that due to the passage in time since the CARF data were collected, and the difference in the dimensions assessed by the Health and Safety Instrument and CARF, there are no relationships between the variables measured.

Address	O1	O2	O3	#	MED	MEDND	#DOC	U1	BP	SAPESCS	SAPIH&S	Aeeee:lPP	Liv	Pr				
Agency 1	4	1	4	0	.66	0	2	6	0	2	0	.1	1	9	0			
Agency 2				0		0	.6	.6	0		0	.5	0	23	10	14	34	
Agency 3				0	.81	0	.2	9	6	0		0	.63	0	27	14	11	35

## Conclusions

Wyoming has made very strong initial steps toward measuring quality of supports and services to their citizens with developmental disabilities. The participation of community providers in the CARF accreditation process over the past decade indicates a strong desire to strive for the delivery of quality supports. Their search to measuring quality is ongoing, and they have tried a

number of approaches such as the use of the RLI for a month which was never continued primarily because of the perceived excessive amount of person hours necessary in collecting the data. The UAP 's proposal to measure outcomes which would include a modification of the 1992-1994's primary contact satisfaction survey is an indication of the state's evolution toward measuring quality on an outcome basis. However at present there is no systemic effort.



# REPORT ON AC SURVEY REPORT

## Overview

The purpose of this visit was to observe the implementation of the Accreditation Council's new Outcome-based Performance Measures (1993). The design, development and adoption of the Outcome-based Performance Measures involved a two-year process which began in 1991. Through focus groups and individual interviews with individuals with disabilities, outcomes were identified that people expect from the services and supports they receive. The Council received input on successive drafts of the proposed measures from people with disabilities, families, service providers, representatives of state and federal agencies and other professionals. The outcome measures were adopted for use in accreditation reviews in July, 1993. The Council conducted field tests of the standards prior to their final adoption. The purpose of the field tests was to insure that the measures were valid, reliable and applicable across settings. The field tests occurred in ICFs/MRs, supported living, supported employment and service coordination settings.

Prior to the adoption of the Outcome standards, the accreditation process focused on organizational activities, resources and services. The measures of assessment, planning and training addressed quality in terms of what the organization had achieved, not in terms of outcomes for the person receiving services. This shift represents a significant change in the way accreditation now occurs. The individual receiving services and supports now dictates what is measured and what is observed.

## The Survey Outcomes and Process

As a result of the work done by the Accreditation Council, the following outcomes were identified for individuals:

1. People choose personal goals.
2. People realize personal goals.
3. People choose where and with whom they live.
4. People choose where they work.
5. People choose how to use their free time.
6. People choose services.
7. People choose their daily routine.

8. People participate in the life of the community.
9. People interact with other members of the community.
10. People perform different social roles.
11. People have friends.
12. People remain connected to natural support networks.
13. People have intimate relationships.
14. People exercise rights.
15. People are afforded due process if rights are limited.
16. People are free from abuse and neglect.
17. People are respected.
18. People have time, space and opportunity for privacy.
19. People have and keep personal possessions.
20. People decide when to share personal information.
21. People have health care services.
22. People have the best possible health.
23. People are safe.
24. People use their environments.
25. People live in integrated environments.
26. People have economic resources.
27. People have insurance to protect their resources.
28. People experience continuity and security.
29. People are satisfied with services.
30. People are satisfied with their personal life situations.

In addition to the individual-specific outcomes, The Accreditation Council also identified Performance Measures for Organizations. These include:

### **Personal Health, Safety and Welfare**

1. The organization protects the rights of people.
2. The organization demonstrates a commitment to using positive approaches in all services and support activities.
3. The organization's service practices and staff demonstrate sensitivity and concern for personal dignity and respect.
4. The organization implements procedures for investigation and intervention in all instances of alleged abuse and neglect.
5. The organization owns, operates or leases buildings that comply with all applicable fire and sanitation codes.
6. The organization implements procedures for meeting all emergencies, such as fire, severe weather and health.
7. The organization implements employment screening procedures that minimize unnecessary or unreasonable risk.



## **Fiscal Management**

1. The organization has a budgeting and accounting system.
2. The organization has an independent audit of its fiscal activities annually.
3. The organization has separate accounting for funds managed for people.

## **Human Resources Management**

1. The organization's personnel practices meet all state and federal fair labor regulations.
2. The organization provides opportunities for staff training and personnel development.
3. The organization regularly evaluates and provides feedback to its staff on their performance.

## **Planning and Evaluation**

1. The organization has a clear statement of its mission and purpose.
2. The organization conducts an ongoing evaluation of success in achieving desired outcomes.
3. The organization includes input and involvement from people served and others in its evaluation and planning activities.
4. The organization implements a program for continuous quality improvement.

An agency files an application for accreditation review approximately six to twelve months prior to the review. The application includes information about the services and supports the agency provides and information about the people to whom the agency provides supports (gender, age, type of disability). The third section of the application includes information about several of the Performance Measures for Organizations. This enables the Accreditation Council to determine whether the agency is ready for an on-site review, or whether the agency would be better served by first receiving consultation in areas of perceived need for improvement.

In addition to the aforementioned information, the agency supplies The Accreditation Council with a roster of the individuals supported. This assists in the selection of a "representative" group of individuals to be interviewed during the on-site review. In the case of this agency which supports 23 individuals in apartments, 15 individuals in an ICF/MR, and 30 individuals in two 15 person group homes that are certified under the Home and Community-based Waiver, one individual was selected from each of the group homes, one from the



ICF/MR and four individuals were selected from the apartment program, for a total of seven individuals comprising the sample.

The length of the on-site review is determined by the number of people supported by the organization, the scope of services and supports provided and the size of the geographic area in which supports and services are provided. The Accreditation Council determines the number of surveyors and the number of days needed to complete the on-site review process. For the review observed, there were two surveyors for four days on site.

Accreditation Council surveyors are skilled professionals in the field of developmental disabilities. Surveyors must have significant experience in working directly with individuals with developmental disabilities. It is not a requirement, however, that surveyors work in accredited facilities. Of the two surveyors on this review, one worked in state government and the other worked in a large, public ICF/MR. Both of the surveyors had participated in many reviews under the 1990 Standards, and both had participated in multiple reviews under the new outcome-based standards. The Council designated one of the surveyors as the team leader.

Once the application is completed and deemed acceptable for on-site review, the agency receives a set of materials to guide them in a self-assessment process. In the self-assessment process, the agency selects at least three individuals to interview, and for each individual determines whether each of the outcomes is present, and also makes a determination of whether there is a process in place to support the outcomes. The self-assessment is forwarded to The Accreditation Council approximately 6-8 weeks prior to the on-site review. In this particular situation, the agency had never been surveyed using the outcome standards. As a result, they requested that one of the individuals interviewed for the self assessment also be part of the on-site sample. This would let the agency know in a sense, whether they had been "too hard" or "too easy" on themselves for the self-assessment. It is a practice of The Accreditation Council to include in the sample, at least one individual who was a part of the self-assessment process.

### **The Presence and Role of Observers During the On-Site Review Process (The Accreditation Council's Policy)**

The Council routinely sponsors its Board members and potential new staff members to observe Accreditation Reviews. The purpose of observation by Board Members is to assist them in their responsibilities as Council policymakers by ensuring their direct familiarity with the Review process and the

implementation of the *Outcome Based Performance Measures*. The purpose of observation by potential and new staff members is to cooperatively assess their skills and interest in becoming reviewers/trainers and to increase skills of those already conducting reviews or providing training and consultation.

Observers typically participate in the Review by accompanying members of the Review Team as they complete their activities: interviewing people participating in services, discussions with staff members, observations, record reviews, and assessment of *The Performance Measures for Organizations*. There are situations in which the observer is assigned responsibility for particular aspects of the review in order to provide experience and the opportunity to determine skill and comfort level with the process. This occurs at the discretion of the Team Leader in conjunction with the Director of the Accreditation Department and is decided based on the purpose of the observation. No decisions about any aspect of the Review are made by an observer. As in any Review, decisions are made only after thorough discussion of information by the Team.

Observers participate in Reviews in the spirit of The Council's mission to improve quality through a cooperative and consultative relationship.

## **Observation of the Survey Process**

### **Day One**

On the first day of the review, the team members met with the key staff from the agency, including the executive director. This gave everyone at the agency an opportunity to introduce themselves. The surveyors introduced themselves, as did the Temple observer, explaining the role of the observer in the process. The Team Leader gave an overview of the AC on-site review process. The staff were able to provide additional information about programs and services, ask questions and assist in the establishment of the schedule. At that time the sample selection was done, to purposely include one of the individuals who was part of the self-assessment. The team was also informed at that time that six of the individuals supported by the agency did not wish to participate in the on-site reviews. As is the Accreditation Council policy, those individuals were removed from consideration for sample selection purposes.

The purpose of the sample selection is to attempt to reflect the various characteristics of the individuals supported by the agency. In addition, an attempt is made to select individuals receiving various types of residential,



employment and other services and supports provided by the agency. The sample for this review included seven individuals.

Once the sample selection was completed, the individual interviews began. At that point, the two reviewers split up, each interviewing different individuals. The Temple observer accompanied one of the surveyors. The first individuals interviewed preferred to be interviewed at the main office of the provider agency, which is also the location of the agency-supported workshop. The people were interviewed along with the individuals who supported them, at the request of the individuals, and included direct support staff from the day program and residence, and program supervisors. Each of the interviews lasted approximately one hour. The interviews were conducted using the protocols and questions developed by The Accreditation Council. Follow-up questions were asked at the discretion of the team members.

To determine inter-rater reliability, The Accreditation Council has established a policy that team members both interview one individual, with one team member conducting the interview and taking notes, with the other team member observing and taking notes. Both team members participate in all follow-up and observations. After all information has been gathered, both team members independently assess the presence or absence of each of the outcomes and processes. The inter-rater reliability review was completed on the first day.

On the evening of the first day the team visited and interviewed two individuals in their apartments. At the end of the first day, the team members met to discuss how the review had gone, thus far, and what adjustments needed to be made to the schedule for the remaining days of the visit.

## Day Two

In the morning the team members met with the agency management staff to touch base about how the logistics of the review were working. After minor adjustments were made, the individual reviews continued. Observations were made of the day program at the agency in which many of the individuals supported by the agency are involved.

Follow-up surveys were conducted for four individuals. The purpose of follow-up surveys is: "to determine if the normal procedures we use for the review identify the critical issues for people with regard to HEALTH, SAFETY, and ABUSE AND NEGLECT, and if supports and services address the issues." The follow-up was done after the decisions had been made by the team and were



done by the person who did not do the initial interview, to maintain the objective nature of this part of the review. The follow-up for medical issues was done using the individuals' records and included the plan, any medical evaluation reports, consultants' reports and any other relevant medical information. Safety was addressed using the individuals' plans, evacuation drill reports and self-assessments done by the agency.

That evening visits were made to the two group homes and the ICF/MR. The visits were made after individuals had returned home from work or day program, and in some cases, just before dinner. Interviews were conducted in the privacy of individuals' rooms when that was requested. Later in the evening the team members met to discuss the interviews and visits that had taken place that day. Final plans were made to complete the interviews and the Performance Measures for Organizations on Day Three.

### **Day Three**

The team once again split up, and while one team member completed the remaining individual reviews, the other team member met with relevant staff to complete the Performance Measures for Organizations. Once all interviews were completed, both with individuals and staff, the team returned to their hotel to begin the decision-making process. The reviewers discussed their findings on a daily basis, and in many cases assessed the presence of the outcomes for individuals as they had enough information to do so. The reviewers used the Outcome Decision Making Guidelines for making their decisions. For each individual a decision was made of whether the outcome was present. In addition, a judgment was made of whether the organization had a process in place to support the individual in achieving the outcome. As the reviewers made decisions for each individual, they noted specific areas where the agency deserved commendation or needed improvement.

Once all of the assessments are made, the scores are recorded for each individual. The scores are totaled for each individual and then across individuals to develop an organizational profile. The Council has developed a formula for determining a recommendation for accreditation status based on the average number of outcomes present across individuals in the sample. Once a decision is made, a recommendation is presented to the Accreditation Committee of the Council for their consideration and final determination.

This review was particularly interesting, in that the decision-making process of the team resulted in a recommendation that the agency not receive accreditation. This was contrary to the results of the self-assessment performed by the agency.

## **Day Four**

On the last day of the survey, the reviewers are provided with an opportunity to present the information to the staff. Typically a preliminary meeting is held with a small group of key staff and then a meeting is held with a larger group to share the findings of the survey. Because of the results of this survey, it was decided that a meeting would be held first with the Executive Director, leaving the decisions about subsequent meetings to him. The Executive Director decided that the subsequent meeting should be restricted to key staff, i.e., primarily those staff involved in the initial meeting.

## **Impressions and Issues**

Having been only vaguely familiar with The Accreditation Council process, this review provided the Temple observer with an excellent opportunity to observe the application of the new, outcome standards. There is no question that the publication of these standards represents a significant shift from the process-oriented standards that characterized ACDD for so many years. The outcome assessment process is invaluable in focusing the field on the purpose of service delivery to people with developmental disabilities - the production of measurable outcomes. The outcomes measured by the accreditation process closely parallel those developed by the HCFA working group in November, 1993 and refined by the Technical Working Group to this project in November, 1994. Those outcomes include:

Self-determination	Individualism
Dignity	Personal Growth
Health and Safety	Community Inclusion
Consumer Satisfaction	Relationships/Social Connections

The survey process provides an opportunity for organizational growth and development, and the reviewers were able to provide ongoing technical assistance to the agency throughout the process.

However, there are still some concerns remaining regarding the Accreditation process. Some of the issues raised have been observed; others have been expressed by colleagues in the field. First, there are some concerns about the sampling process. It has been made very clear from the beginning of the promulgation of the Outcome Standards that the individuals determine what outcomes are important to them. If this is the case, how can any one assume that the outcomes that are important to one person are generalizable to others? There



are also some concerns regarding the numbers of individuals in the sample. Although the need for making efficient use of time is understood, the stratification that is desired (as reflected in the Outcome Based Performance Measures Manual, page 32) is hardly achievable from a truly scientific perspective. Sampling one individual from each of the group homes, one individual from the ICF/MR, one individual receiving individual support services and three individuals from the apartment programs did not seem to accurately reflect the breadth of individuals supported by this agency. Although there is no immediate suggestion for remediation, short of increasing the sample size, this is noted as an issue.

Secondly, the issue is raised of who conducts the AC surveys. Although the Temple observer is not sure of the particular requirements for surveyors other than years of demonstrated experience providing direct support to individuals with developmental disabilities, there is no requirement that individuals work or have experience working in accredited facilities. This may be a small issue; however, it has been raised as a cause for concern, particularly in the surveyors' role as providers of technical assistance.

Third, the issue of health and safety is raised. There are specific outcomes that address the issues of health and safety (outcomes 16, 21, 22 and 23). In addition to the survey process, AC has focused additional attention on those areas for a subsample of individuals. However, can AC truly profess that in an accredited agency all individuals are healthy, safe and free from abuse and neglect? Can any system make that claim? The question, then, is can the accreditation process be modified in such a way to include more individuals, such that the issues of health and safety are directly addressed? For example, one strategy may be to expand the sample to include those individuals for whom there are behavior programs, high numbers of unusual incident reports or medical fragilities. This may better address the health and safety issues.

Fourth, is the issue of applicability across settings. HCFA is concerned that any system be applicable in all settings, including those supporting people with the most significant disabilities, including those who are non-ambulatory and those individuals who experience speech and communication difficulties. To the best of the research team's knowledge, thus far, no agency supporting more than 120 individuals in one setting has received accreditation under the outcome standards. The remaining question is whether any large facility can receive accreditation.

Fifth, although the Accreditation Council is vigorously pursuing the question of inter-rater reliability, there have been no studies to date of the concurrent



validity of the instrument. It is our understanding that this will be pursued in the future.

## **Description of Data System**

AC data are collected in a way that is amenable to some levels of analysis. Each individual in the sample is given a score, based on the number of outcomes present and the presence of a process in place to support the outcomes. The scores for individuals are summarized to obtain a total score for the agency.

## **Reliability**

The Accreditation Council has been actively involved in assessing the reliability of the outcome standards. As mentioned previously, all reviews include a reliability assessment. AC is also involved in a more comprehensive assessment of reliability. Once the results of the study are made available, they will be forwarded to HCFA. Because AC is in the process of a rigorous reliability study, no further work in this area was undertaken by the study team.

## **Concurrent Validity**

The Accreditation Council is very interested in examining the concurrent validity of the outcome measures, however, that assessment has yet to be completed. As a result, the Temple team has received from AC a listing of those agencies across the country who have been accredited utilizing the outcome measures. After reviewing the list, an agency in Pennsylvania was solicited for their participation in this phase of the study. A data collector went to that facility and collected information about 30 individuals, using the Temple BDS. The 30 individuals were selected by the agency as a sample of convenience. For reasons of confidentiality it was not disclosed whether any of the individuals in this portion of the study also participated in the Accreditation Survey the year before. The agency made available to Temple a full copy of the Accreditation Report, which was issued in March, 1995. The first caution here is that the data collected were collected approximately one year after the Accreditation Survey. There is no doubt that significant change occurred during that one year period.

Once the report was received, the study team spent considerable time discussing how the AC data could be best used for purposes of assessing concurrent validity. The first step in this process was to categorize the 30 AC standards into

the valued outcomes developed by the HCFA working group. The categorization is as follows:

## **HCFA OUTCOMES**

## **AC OUTCOMES**

### **Self-Determination**

People choose personal goals.  
People choose where and with whom they live.  
People choose where they work.  
People decide how to use their free time.  
People choose services.  
People choose their daily routine.  
People decide when to share personal information.

### **Personal Growth Integration**

People realize personal goals.  
People participate in the life of the community.  
People interact with other members of the community.

### **Dignity**

People live in integrated environments  
People perform different social roles.  
People exercise rights.  
People are respected.

### **Relationships/Social Connections**

People have economic resources.  
People have friends.  
People remain connected to natural support networks.

### **Health and Safety**

People have intimate relationships.  
People are afforded due process if rights are limited.  
People are free from abuse & neglect.  
People have health care services.  
People have the best possible health.  
People are safe.  
People have insurance to protect their resources.

### **Individualization**

People experience continuity and security.  
People have time, space and opportunity for privacy.  
People have and keep personal possessions.  
People use their environments.



**Satisfaction**

People are satisfied with services.

People are satisfied with their personal life situations.

Once the AC data were categorized into the outcomes identified by the HCFA working group, the study team began to analyze the data. In the AC process, for each individual outcome, a determination is made as to how many individuals in the sample achieved the outcome. Additionally, a rating is given to the number of processes in place to support the achievement of the outcome. For this study, the team calculated the scores for each of the HCFA outcomes. In order to do this, for each item in the outcome the number of outcomes were summed with the number of processes present. Those sum scores were then divided by the total number of items comprising the outcome, to produce a percentage score against which other measures (in this case the Temple BDS) could be compared. The analysis yielded the following information:

Outcome	AC Percent	Temple Percent
Individualization	77	28
Health & Safety	84	93
Satisfaction	82	54
Personal Growth	73	
Relationships	64	
Integration	43	20
Self-Determination	55	27
Dignity	49	97

The two areas where there is the greatest correspondence are the areas of health and safety and integration. In the other areas, there is little to no relationship. These data must be interpreted with extreme caution. As mentioned previously, the two types of data were collected one year apart. Second, the samples were both purposive, but in different ways. The AC survey attempted to include individuals from a variety of settings (7 people from community settings, 5 from the large ICF/MR and 3 who receive day services only); the Temple sample was originally to include equal proportions of individuals in community and residential settings. However, as data were being collected a snowstorm arrived, necessitating more data collection in the large ICF/MR where staff were available for interviews. The result of collecting 2/3 of the data in the large ICF/MR setting is reflected in particular, in the dimensions of individualization, self-determination and dignity. Third, the AC process actually yields a facility rating rather than individual ratings. As a result, the one AC score is compared to 30 Temple BDS scores; hence no correlations were possible.



In summary, we encourage the Accreditation Council to continue its pursuit of the assessment of concurrent validity of the Accreditation process. The study team would be pleased to collaborate with the Accreditation Council in this effort.

## **Applicability**

As mentioned previously, thus far no large agency or facility (larger than 120 individuals) has been accredited using the outcome standards. Because of the intensity of the accreditation process and the need for highly trained surveyors, it is impractical for the Temple team to conduct an AC assessment. At this point it is questionable as to whether these standards can be applied successfully in a large setting.

## **Discriminant Validity**

The Accreditation Council does not maintain quantitative scores for agencies. Rather accreditation is given for a one or two year period. In addition, a decision is made for an entire agency. Therefore, the data emanating from AC surveys are not amenable to this type of analysis.



# CARF SURVEY REPORT

## Overview

The purpose of this visit was to observe the implementation of the new (1995) standards for community support accreditation from CARF. These new standards were developed by national consensus and represent a major change in the method of review and the measures of quality for the CARF survey. Previously, the review was based primarily in documentation review in order to establish compliance with standards. The revised standards are based in interview with staff and the service/support recipients using documentation as the source of proof for planning, involvement of consumers and family in choice and decision-making, staff training and health and safety issues. The CARF survey in Minnetonka, Minnesota occurred between July 24 - 26, 1995. During the three day visit, Robin Levine, a Temple staff person was part of all planning and discussion meetings and accompanied the residential reviewer to all agency residential sites.

## The Survey Standards, Structure and Process

The CARF survey is a peer review conducted on site by a team of reviewers. The number of reviewers and days for the review are determined by CARF staff based on the size of the organization and the number of programs to be reviewed. The site review team was comprised of three reviewers, each responsible for one area of program (administration, residential and vocational supports). CARF reviewers are required to work in CARF accredited agencies and hold positions in direct correspondence to their area of review. Including people with disabilities and family members as reviewers is being considered by the CARF Board of Directors.

All CARF surveyors are required to perform a minimum of three surveys per year. This is set forth due to the amount of time and resources expended to train each reviewer. Training of new reviewers takes place over five days at the CARF National Office in Tuscon, Arizona. The training is paid for by CARF and generally includes 20 to 30 people in the trianing group. The training includes a thorough didactic review of the standards followed by a two day expereintial role play of the team dynamic and survey process. This two day role play includes writing examples, introduction and exit meetings, communication techniques and active listening. Trainees receive feedback on their performance throughout the training. At the end of the five days if the trainee is accepted as a reviewer, he/she becomes an intern with a seasoned surveyor identified as a mentor. Over the next three to six months the Intern participates in two to three surveys as a regular team member. The performrance



during each review is critiqued by the mentor, other team members and the organization. At the end of the internship period, the reviewer can graduate (becoming an approved CARF surveyor), receive counseling toward improved performance or continue in the internship program. Additional training has been required since 1994, after the new standards were adopted by CARF. This continuing education is provided in Tucson and at other regional locations by CARF staff. All surveyors are required to attend one continuing education training every three years.

The three reviewers at this review were experienced CARF surveyors, each having participated in more than 30 reviews over the past years. The administration reviewer is identified as the team leader and takes responsibility for overall scheduling, team meetings and final report writing. This was the first review for all the reviewers utilizing the new standards. All expressed initial concern about effective implementation of the new standards but expressed their overall belief in the strength and applicability of the CARF survey.

The survey standards are based on four overarching accreditation principles and eight accreditation criteria (this is the substance of the administrative review). The eight accreditation criteria must have written policies to document conformance with the standards and these policies are submitted to the review team in advance of the review. The eight policies are: 1) input from the persons served; 2) accessibility; 3) outcomes; 4) rights, health and safety; 5) human resource development; 6) leadership; 7) legal requirements; and 8) financial planning and management. If one or more of these policies do not exist, the agency accreditation is placed on a 60 day hold until conformance is achieved. The survey is designed to measure quality outcomes in three identified core areas. The core areas to be reviewed during this survey were Promoting Organizational Quality (administration), Promoting Service Quality (consumer satisfaction and service outcomes) and Specific Services/Program Standards (residential, employment, personal and social issues). All agencies must be reviewed for organizational quality regardless of which service/support program is being specifically accredited. Each core area has a set or several sets of standards (criteria) with interpretive guidelines. The standards for Promoting Organizational Quality have been described in the eight policies identified above. Promoting service quality addresses two standards: 1) individual-centered planning, and 2) service design and delivery. Specific Services/Program Standards identify 14 standards in the area of community support services. The first 9 of 14 standards address supports to the person served in the areas of: 1) tailored support services, 2) assistive technology and reasonable accommodation; 3) support in decisionmaking; 4) informed choice; 5)

learning new skills; 6) self-sufficiency; 7) relationships; 8) resolution of conflicts; and 9) risk to health and safety. Five of the 14 standards measure organizational support to the person in their ability to 1) demonstrate positive changes (data collection); 2) assist in maintenance of assistive technology and equipment; 3) provide services based on the concept of natural proportions; 4) promote community inclusion; and 5) develop or facilitate access to community supports.

The task of the review team is to determine conformance or non conformance with the standards based on their interviews, record review, observations and judgment. Ratings of conformance can be accompanied by a commendation for best practice. A rating of non-conformance is given with either a suggestion for improvement (does not require follow-up) or a recommendation (requires a 90 day corrective action plan). The corrective action plan is compared to a quality improvement plan. The team writes a report of their findings prior to leaving the site visit. This report is shared with the management staff of the organization during the exit interview. It is customary for the Executive Director to have a private exit interview in advance of the larger staff exit interview. The site reviewers' report is submitted to the CARF national office to be revised into "CARFese" by editors. This is done in an effort to bring consistency in form and language to all reports. This revised report is then submitted to the CARF Board of Directors who is the accreditation granting body. The team makes a recommendation of a non, one, or three year accreditation to the Board but it is the Board who makes the final decision.

## **Documentation and Observation of the Site Review Process**

In advance of the on-site review, the agency completed a self-study questionnaire which was distributed to the site review team along with general agency brochures.

### **Day One**

The team held an introductory meeting for all key management and program staff on the first morning of the review. This meeting included the process and goals of the review, introduction of the reviewers and Temple observer, introduction of all agency staff at the meeting and a presentation from the Executive Director on the agency history, mission, goals and objectives.

After this introductory meeting the three reviewers were given individual schedules prepared by the agency which would take them to all the program sites of this agency. Agency staff accompanied the reviewers to each location allowing for individual staff interviews during the driving time.



At the end of Day 1, the reviewers met back at the hotel in the evening for a debriefing. At this time the team leader checked in on scheduling needs and emerging problems were identified. In this case, and much to the surprise of the team, this agency exhibited serious administrative, program and health and safety issues. The most significant issue, both in terms of overall health, safety and quality of life for people, was a 100-bed facility that the team had dinner at that evening. The facility included 50 one-person rooms and 50 two-person rooms of equal size. In touring the facility the agency staff were working hard to compare this facility to a college dorm and to highlight all the choices and satisfaction that the people were experiencing. What was observed was an outdated facility with poor ventilation, heating and cooling, cramped rooms, outdated electrical fittings and a pervasive smell of urine. All the reviewers expressed their dismay with this facility and were prepared to identify the specific standards that would support a finding of non-conformance in several core area standards. It was agreed that the team leader would begin to give this information to the Executive Director in an effort to prepare him for the final report which would include many recommendations requiring the 90 day plan of correction.

## **Day Two**

The site review team members followed their individual schedules of site visits and interviews for the day without conferring with one another. The residential reviewer returned to the large facility to review records in addition to seeing several other group homes and supported living sites. In all sites he talked to people about their choices and satisfaction and then looked for documentation to corroborate their involvement. In each residence fire safety, medications administration and emergency evacuation procedures were investigated. Unfortunately, the reviewer did not always meet the people who lived in these homes due to limited time. It is not required that the reviewer meet people in every location.

At the end of Day 2 the team met again to discuss remaining programs to be visited and to build consensus on the overall evaluation of this agency. The responsible team member went through each standard and guideline and described the conformance or non conformance rating. This seemed to be a particularly beneficial process in that new information was shared among site reviewers. Interestingly, the review team members said that this was the first time they had ever done this type of reconciliation. Perhaps it was needed due to the new standards and process or because of the serious problems identified within this agency. After the discussion of individual ratings each team member made their recommendation for number of years of accreditation. Following this meeting the reviewers began to write their individual reports to be finished and reported in summary on Day 3.



### **Day Three**

The morning was spent finishing up site visits and collecting documentation that was found to be missing during report writing. Final reports were written and submitted to the team leader.

A pre-exit interview giving a brief description of the findings was held with the Executive Director prior to the staff exit interview. At both meetings the reviewers were very purposeful in speaking as "we the team" and framing the CARF survey as an opportunity for growth and improvement.. Each reviewer read their report in its entirety with added extemporaneous comments. Site reviewers were available for a short time after the exit interview to discuss specific findings and accept additional documentation.

### **Description of Data System**

As described in the summary of the site visit, CARF surveys do not result in a quantification of ratings. The ratings of individual site reviewers for each measure is maintained by the reviewer if additional information is requested by the CARF Board of Directors. The report from the site review team is written in narrative style. Specific measures are identified only in the case of a recommendation or commendation. The measures that are not specifically identified are included in a summary overview and rating of each section.

### **Reliability**

Reliability of the CARF review was not conducted by Temple because of two factors. First, as previously described, the CARF survey process is conducted by a team of peer site reviewers who have undergone extensive training and are working in CARF accredited agencies. From a research perspective, it would be inappropriate to have Temple data collectors assume the role of a CARF reviewer without the same level and degree of training and without the experience of working in a CARF accredited facility. Additionally, a CARF review takes many days to complete and requires the total commitment of the agency under review. It would not be within acceptable research protocol to request that an agency undergo a second CARF survey for purposes of establishing reliability of the instrument. It would be worthwhile, however, as CARF continues to utilize the outcome standards to undertake such an effort.

## **Concurrent Validity**

In order to demonstrate concurrent validity, the extent to which the CARF instrument measures the same underlying dimensions as other instruments with established statistical properties, CARF data were compared to the Temple University Behavior Development Survey (BDS). In order to accomplish this, a quantification of the CARF ratings and the collection of the Temple BDS in a CARF facility accredited by the 1995 outcome based standards was conducted.

With the assistance of administrative staff at CARF, an agency was identified that had been reviewed using the 1995 outcome based standards. This agency was approached by Temple staff and agreed to participate in the concurrent validity analysis. The agency also agreed to provide us with the actual CARF report from which we would compare findings. In March 1996, a Temple data collector spent three days in this facility which provided community living services and supports to people with varying degrees of mental retardation. Data were collected in state-funded group homes and in federally funded ICF/MR programs. Thirty Temple University BDSs were collected about individuals in this agency who were residing in the agency at the time of the CARF review.

In order to compare the six domains of the Temple University BDS which addressed the valued outcomes identified by the HCFA Working Group, CARF standards have been classified into the following comparable Temple BDS domains.

<b>Domain of Temple BDS</b>	<b>Comparable CARF Standards</b>
Health and Safety	1B - Accessibility 1D - Rights, Health and Safety 3B.9 - Assessment of Risk to Health and Safety 3B.32 - Individual Health Care and Safety
Individualization	1A - Input of People Served 2A - Individual-Centered Planning 3B.1 - Individually Tailored Supports 3B.2 - Assistive Technology/Reasonable
Accommodation	3B.3 - Decision Making 3B.4 - Informed Choice 3B.11 - Appropriate Assistive Technology 3B.30 - Personal Space and Privacy 3B.31 - Alternate Living Opportunities



Integration/Inclusion	3B.12 - Natural Proportions in the Community 3B.13 - Promotes and Facilitates Inclusion 3B.14 - Access to Community Supports
Relationships/Socialization	3B.7 - Meaningful Relationships 3B.8 - Resolution of Conflicts
Personal Growth	3B.5 - Learn New Skills 3B.6 - Self - Sufficiency
Consumer Satisfaction	1C.7 - Use of Consumer Satisfaction Information 2B -Evaluation of Consumer Satisfaction and Outcomes 3B.10 -Demonstrates Positive Changes

The most complex task in this analysis was actually quantifying the CARF review. The results of the review are provided in a narrative format. There are no raw scores provided. Each standard is discussed in paragraph form but each criterion within the standard is not necessarily noted or referenced. A final rating for each standard is not explicitly noted while rating language is implicit throughout the narrative report. For purposes of this analysis the narrative report was thoroughly reviewed by Temple staff. Within each category ratings were given if an explicit recommendation or commendation was specifically tagged to an individual standard. If a specific recommendation or commendation was not noted it was determined that the agency had conformed with the standard and the corresponding rating was attributed. For purposes of comparison to the score in each of the six domains of the Temple BDS the following numeric rating scale has been developed for the CARF ratings.

- Conformance with Commendation = 4
- Conformance = 3
- Conformance with Suggestion = 2
- Non-Conformance with Recommendation = 1

In the analysis of this data, we calculated the sum scores of the ten Temple BDS domains from BDSs collected at the CARF accredited agency. We also computed the sum scores of the seven Health and Safety scales also collected at the CARF agency. For the ratings attributed to the original CARF survey, we calculated the mean score and percentile ratings for the six categories identified. The table below displays the preliminary findings of this analysis.

HCFA Work Group Outcome Domains	Percentile (CARF Survey)
Individualization	80
Health and Safety	74
Satisfaction	73



Personal Growth	67
Relationships	50
Integration	67

Temple BDS Domains	Percentile (Temple BDS)
Dignity	100
Adaptive Behavior	73
Challenging Behavior Frequency	77
Challenging Behavior Severity	87
Frequency of Integrative Activities	38
Consumer Satisfaction	62
Individualization	62
Self Determination	44
Medications	70
Med Needs	99
Behavior Plan	88
Safety Scale	96
Safety of Neighborhood	76
Health and Safety Mean Score	86

There are four categories of the HCFA domains that can be compared to the Temple BDS domains. Health and Safety in the CARF survey (74) compared to the Health and Safety Mean Score from the Temple BDS (86). Individualization on the CARF survey yielded a score of 80, compared to a score of 62 on the Temple BDS. The Satisfaction measure on the CARF survey was 73, while the Temple BDS score was 62. Integration on the CARF survey was 67, with a score of 38 on the Temple BDS. Integration scores produced the most disparate findings.

While it took considerable effort to match CARF standards to Temple BDS items, it appears that there is some level of correspondence between the outcomes of health and safety and consumer satisfaction. However, it bears repeating that the CARF survey process does not yield quantitative outcome measures.

## Applicability

The CARF review process is conducted in agencies that offer a variety of living supports to people with varying degrees of mental retardation including group homes and ICF/MR facilities. The CARF review has been found to be applicable to these settings.

## **Discriminant Validity**

Due to the fact that CARF ratings are not quantified and do not generate numeric raw scores, a discriminant validity analysis is unable to be conducted.

It is recommended that CARF continue to evaluate the statistical properties of the outcome based system.

## **Conclusions**

This process was found to be thorough and valuable to the agency from a quality assurance and growth perspective. The reviewers were highly qualified, comfortable and capable in talking with people with disabilities and staff, and thorough in their review of materials. Due to their own work experiences and national perspective gained from conducting CARF reviews they were able to provide technical assistance to staff throughout the visit. There is a high level of confidence that this review team had identified the health and safety problems for the people receiving services/supports from this agency and was able to fairly measure the quality of life opportunities and obstacles for these individuals as identified in the CARF standards.

There are two areas of concern that emanate from this review. Inter-rater reliability as it relates to the guarantee of quality and safety is the first issue. It is uncertain how a different set of reviewers would have judged the quality of these programs as each reviewer brings a different set of experiences, biases and preferences to the review. While this is addressed during training of reviewers, it is problematic that three years ago a site team recommended three year accreditation to this agency. Although the standards and process have been greatly revised, the health, safety and quality issues identified in the large facility were present at the time of this previous review.

The second issue raised is about the underlying premise in the development of these standards. Is this survey meant to advance or reflect the field? This issue became clear on the first day when the team toured the sheltered workshop. This was the cleanest, most technology advanced workshop the Temple observer had ever seen. People were busy doing real factory work. However, it was segregated from the community and even within the workshop ("the autistic program" was isolated into a different area of the room), people were not being paid minimum wage and goals were still developed for individuals based on a readiness model. On the other hand, this agency has made good strides in supported/supportive employment and will continue to expand this program. This agency has not considered including people without disabilities in this factory or increasing the pay for workers. These kind of suggestions were not made by

the site review team as this level of quality and state of the art practices are not explicitly reflected in the standards nor are they necessarily part of the belief system of these individual reviewers.



**APPENDIX D**

- 1 COMMENTS TO HCFA ON DRAFT REVISIONS TO THE  
SURVEY PROCESS FOR ICFs/MR**
- 2 COMMENTS ON REVISED CONDITIONS OF PARTICIPATION  
FOR ICFs/MR**



## COMMENTS TO HCFA ON DRAFT REVISIONS TO THE SURVEY PROCESS FOR ICFs/MR

### General Comments

The approaches outlined in the Draft Revisions appear to be a clear improvement over current survey procedures. They also appear to move in the same general direction of the states in quality assurance for residential services to comparable populations, including:

- The use of a smaller group of essential standards.
- The stronger focus on outcomes.
- The greatly increased focus on interviews and observation, rather than document review.
- The retention of the comprehensive survey and its availability to surveyors when problems are observed using the Fundamental Survey Process.

There are also some guidelines that appear to emphasize aspects of the ICF/MR standards that are particularly consistent with contemporary values and outcomes that are important to individuals with mental retardation/developmental disabilities, as well as the primary outcomes identified by the Technical Working Group advising the current HSRI project on quality assurance in the ICF/MR program:

- |                         |                                    |
|-------------------------|------------------------------------|
| • Individualization     | • Health and safety                |
| • Self-determination    | • Relationships/social connections |
| • Dignity               | • Consumer satisfaction            |
| • Integration/inclusion | • Personal growth                  |

Overall, however, it appears that the emphasis on individualization, relationships/social connections, self-determination and community inclusion/integration is relatively weak. Although mentioned in some components of the Draft Revisions, these themes are not consistently emphasized throughout. Suggestions on how this emphasis could be enhanced are provided below.

As discussed in the comments on Part IX of the Survey Process and on the Suggested Interview Questions, we recommend that additional thought be given to the use of interviews with people with communication limitations and/or who use different modes of communication, as well as those with more severe levels of cognitive disability. If interviews are going to become the primary tool for surveyors along with observations, it is important to provide guidance on how to apply these techniques for the many thousands of ICF/MR residents who will have problems responding to the kinds of questions that are listed.



Finally, we recommend that HCFA consider some use of process indicators, at least in the guidelines to surveyors, specifically those procedures that are directly tied to target outcomes, such as how and what staff know about individual communication, preferences, strengths, choices, and interests. The continuing need to examine process even in an outcome-focused survey is acknowledged, for example, by the Accreditation Council in the survey procedures for its 1992 standards. A few suggested questions on process that might be included in the guidelines to surveyors are noted below in relation to specific sections of the Draft Revisions.

### Facility Compliance Principles

This section provides good guidance overall. We recommend that it come first and that it apply to all surveys, not just Extended and Full Surveys. The references to choice, community involvement, and relationships in W122, and to independence, communication, coping, social and leisure skills in W266 are appropriate, and should be mirrored in guidance for the Fundamental Survey Process.

The guidance on meeting the CoP of Active Treatment also should include the concept of choice. This is consistent with references to choice and self-management in W247. We also recommend that HCFA consider that independence includes more exercise of choices, and that active treatment should be promoting and supporting choice-making. This is stated in guidance on when the CoP is not met; we recommend that it also be stated explicitly as an indicator of compliance.

Since the Comprehensive Functional Assessment (CFA) and the IPP objectives are still referenced as the basis for assessing Active Treatment compliance in the Revised Survey Procedures for Full Surveys, surveyors may continue to consider the CFA and IPP objectives in assessing Active Treatment even if not specified. We would therefore recommend that choice, independence and growth in decision-making as part of the CFA and objectives that underlie Active Treatment provision and outcomes be explicitly stated. I.e., if choice and self-management outcomes are present, they begin in looking at individual choices in developing the CFA and IPP. This is also consistent with the focus on self-determination and independence in the IPP standard (483.440(c)(4)). Individual participation as referenced in W209 and related guidance also may be worth mentioning as a significant indicator as well.

### The Certification Process

#### Overview

On "Emphasis, Components and Applicability"/1st paragraph, would revise 3rd sentence as follows:

The focus of the survey is to determine whether the facility is actually providing active treatment and other required services **on an individualized basis** rather than whether the facility is capable of providing them.

## I. INTRODUCTION

Would revise 1st sentence as follows:

This revised ICF/MR survey protocol is to assist surveyors to focus attention on the outcomes of **individualized** active treatment services.

4th paragraph - would add sentence on what DD field is emphasizing:

In addition, services in virtually all states are placing increased emphasis on person-centered planning and person-centered services, focusing on the preferences, goals and aspirations of each individual and on supporting them in reaching their personal goals.

Also would add re: QA trends:

QA is placing increased emphasis on outcomes related to choice, control, relationships, community inclusion and satisfaction with life, as well a satisfaction with services and supports. Many QA systems also include self-assessment and continuous quality improvement components.

## II. BACKGROUND

In reviewing CFA as the basis for the IPP, it is appropriate to look ahead to self-determination and independence, and therefore to add the concept of identifying individual preferences and choices. These concepts are at least referenced in current W219 guidance (re: affective development) and implied in W227 et al. with references to individual objectives. The point is to ensure that choices and preferences are assessed consistent with the concept of individualization.

These same recommendations also are appropriate for the review of the IPP.

## III. PRINCIPAL FOCUS OF SURVEYS

The 1st paragraph on page 6 is on target by talking about how the individuals, families and guardians participate in identifying and selecting services. If this is truly the focus for principle attention, however, it should be better reflected in the discussion of the standards for CFA, the IPP, and Active Treatment.

On page 7, the description of methods is generally a strong improvement. We would suggest, however, that at least a cursory/background review of data on the individuals in the sample be made, for guidance in what and how to interview, and to look for in observations. Would make similar slight modification on page 9, and related clarification to page 19. I.e., making a brief - not detailed - review specific to identifying implications



for interviews and observations. This is in addition to asking the consumer and the direct care staff, methods which we strongly support.

#### IV. SURVEY PROCESS

The list of CoPs/fundamental requirements generally seems very appropriate: core standards that also lend themselves to interview and observation. Recommended additions:

- W136: Participation opportunities in social, religious and community activities.
- W152: Re: criminal convictions of staff.
- W240: Including promotion of independence in IPP.
- W261: Designation of committee to review behavior management plans.
- W264 and W265: Responsibilities of the specially designated committee.
- W286 and W287: Prohibition on using medications/restraints for discipline or convenience.
- W316 and 317: Re: gradual withdrawal of psychotropic medications.
- W375 and 376: Re: reporting of medication errors.

In addition, we recommend a clarification that W436 includes positioning. If this is not appropriate, then W246 is needed (consistent with retention of W153).

The revised approach described on page 9 re: no further review of supporting requirements is very commendable. We would suggest clarification, however, that interviews and observations include some on the processes that are linked to desired outcomes, especially around choice, individual communication, preference, and consistency across program areas. Questions on how choices are made, how preferences are communicated, how individuals are learning how to exercise their rights, etc., help surveyors get a picture of much active treatment is, in fact, being individualized and is helping people become more independent and have more self-direction.

Re: the ICF/MR recertification survey priorities on page 9, it is not clear how these relate to the previous paragraph on no further review of supporting requirements or related CoPs.

Re: triggering an Extended Survey Process (p. 9), we would suggest an interim step of conducting further investigation when the surveyors are not sure about compliance, rather than going directly to the extended process. Through using the matrix described on page 40, and the guidelines on compliance in the Facility Compliance Principles, most decisions should be resolved without going over all the relevant tags. Further investigation (additional interviews and observations, limited document review) should be able to resolve the rest. The concern would be that, as presently worded, surveyors will revert to the Extended Survey when they are short of a clear-cut decision, rather than trying some further investigation. We would recommend as well that the Extended Survey Process be triggered primarily when surveyors are doubtful that they can find the



ICF/MR in compliance, using the full set of relevant tags. This is responsive to surveyors' concerns that they may need to have extensive documentation when citing non-compliance on a CoP, without encouraging full-blown traditional surveys (especially on Active Treatment) just because of a few unresolved questions. This recommendation also is made for the description of Recertification Surveys on page 11.

The guidance ("NOTE") at the bottom of page 10 is important. We recommend that it be moved up to somewhere in the opening discussion of the different types of surveys. It could be combined with the recommendation in the previous paragraph on conducting further investigation whenever there are questions on the core areas of compliance.

#### VIII. TASK 3: DIRECT INDIVIDUAL OBSERVATIONS

The focus on observations, including off-site program areas, is very appropriate. In line with previous recommendations, we suggest clarification that a  cursory  record review of individuals in the sample may be helpful, just not a  detailed  one.

Re: determining if the necessary relationship between individual needs and what staff know and do with individuals is being made (page 19), would recommend adding individual needs **and preferences**. An example of guidance to surveyors on reviewing active treatment and behavioral programming that includes looking at individual preferences from Module 6D of surveyor training materials (HCFA, 1993) is attached.

#### IX. TASK 4 - INTERVIEWS

Here (and elsewhere where interviews are discussed) we recommend the addition of some guidance on using interviews with people who have very limited or challenging communication. In large public ICFs/MR, for example, where 80-90 percent of the individuals may have severe or profound mental retardation, interview procedures will need to be modified, and surveyors (and the ICF/MR) need to be looking at communication through multiple modes. We recommend using the ICF/MR Surveyor Training Module on communication for suggestions.

#### XII. TASK 7 - RECORD REVIEW

These are very helpful revisions.

#### XIII. TASK 8 - TEAM ASSESSMENT OF COMPLIANCE

On page 30, re: additional information and/or documentation, we recommend that HCFA consider suggesting additional interviews: family members, guardian, friend-advocates, etc., as well as possibly interviewing additional consumers and direct care staff members.

On page 31, we urge that the Facility Compliance Principles (and possibly also the Decision-Making matrix) apply to the Fundamental as well as to the Extended and Full Surveys.

Re: behavior management approaches on pp. 32-33, we recommend adding questions on reliance on aversives, the absence of positive teaching approaches, and the lack of opportunities for independence, choice and decision-making.

Re: environmental importance on page 32, we recommend adding a question on individual environmental preferences and possible interference with active treatment, as well as the significance of assistive technology, adaptive devices/equipment and positioning.

On page 34, the reference to "practice standards" is unclear.

#### CONDITION LEVEL DECISION MAKING

The matrix and definitions on pp. 40-41 generally seem appropriate. We suggest that HCFA consider adding examples of how the matrix would be used in relation to different CoPs, as well as clarification on what is meant in the definition of severe re: "it is likely those negative outcomes will result in the near future."

Facility Compliance Principles - see above.

Revised Survey Procedures - W195 - W196

This generally seems appropriate, however, it is not clear how it is intended to be used. We would recommend adding "privacy" and "relationships" under Rights, "choices and preferences determined?" and "positive teaching strategies?" under Program.

#### Suggested Interview Questions

As noted elsewhere, we suggest that HCFA provide considerable additional guidance, including examples, of how to do alternative interview-type data collection with consumers with severe and profound mental retardation and limited or challenging communication. Alternatives should include discussions with direct care staff, family members and/or friend advocates or guardian about how the facility determines individual choices and preference, strengths, personal goals and interests, etc., and how these are respected and built upon in assessing and promoting individual rights, and in delivering active treatment. We also recommend that a very brief review of the consumer's record be made for some quick guidance on communication modes. As noted above, we suggest that HCFA incorporate some of the suggestions in the ICF/MR Surveyor Training module on communication, including the videotape. These materials cover communication guidelines for surveyors in interviewing consumers as well as suggestions on what to look for in staff interactions and descriptions provided by staff



re: communication and their understanding of individual preferences and needs expressed by consumers with challenging communication.

We recommend adding questions to staff, especially direct care staff, in each area covered, and to friend/advocates when consumers' circles of support includes such people. Some additional suggestions on specific sections are as follows:

1. W124-128

Individual Served

We recommend expanding more on the question of things the person would like to do more often. Re: W125, we suggest asking more on individual interests and choices. Language also should be modified on "going to church," recognizing that this term is limited to specific religious faiths. We also would note that the Constitutional right to freedom of religion is more than just going to services. The last three questions on money seem more appropriate to W-126.

Family Member

We recommend adding a question re: W124 on who provides consent when needed, the individual or family member/guardian, and if consent has been needed and obtained for any programs or treatments. We also suggest asking them if there have been any incidents involving possible abuse or punishment, and if so, were they able to obtain sufficient information, and was the concern addressed.

2. W126

In addition, would recommend adding questions for W127-128 on abuse/punishment, unnecessary drugs and physical restraints.

3. W133, W146

In this same area, we recommend adding W136 to list of tags in Fundamental Survey and adding questions here on participation in social, religious and community activities.

4. W143 [also seems to relate to W209]

We recommend adding the following question:

If not attending the meeting, how were your views on goals, preferences, personal needs and choices expressed and included in the Interdisciplinary Team meeting?  
[modified, as needed, depending on level/style of communication]



For family members, we recommend adding a question on the team's receptivity and attention to their relative's (i.e., the consumer's) views, how their choices were used, extent to which the individual's goals and preferences were the focus of the team meeting's discussion, etc.

5. W144

Individual Served

The question seems to fit more with W127.

6. W147 and 8. W247.

These questions also seem relevant to W136, which we recommend adding to the Fundamental Survey, re: participation in community and social activities and having relationships.

9. W263

Individual Served

This question seems too parental in tone. It is also not clear how this relates to W263.

Family Member

We recommend adding questions on any use of restraints or other aversive stimuli, and possibly asking an open-ended question on what kinds of positive teaching strategies (with example) are being tried.

Overall, this section seems to need much more work than the other components of the revised survey procedures.

EXCERPT FROM MODULE 6D  
ICF/MR INSTRUCTOR'S MANUAL  
FALL 1993





Behavior doesn't just "happen." Internal or external factors - or a combination of the two - trigger a set of responses to a given event or stimulus. By changing the context, changing the stimulus or its presentation, or modifying what happens after the behavior occurs, the behavior itself can be changed.

Let's consider a typical scenario. Every evening you watch television at 7 p.m. for half an hour. During this time you see at least three commercials for food. Tonight you see a "bake someone happy" commercial for a chocolate cake. After seeing the commercial you decide that you want something to eat and go into the kitchen in search of something resembling chocolate cake. To eat the cake, you will have gone through at least some of the following steps:

1. Decided that you wanted something to eat
2. Decided that you wanted to eat more than you wanted to continue watching television
3. Moved from where you were watching television to the kitchen
4. Searched for food
5. Determined what you wanted to eat
6. Prepared it, if necessary
7. Ate the food

Behavior is prompted by a chain of events or activities. One way to examine behavior, particularly inappropriate behaviors exhibited by people with mental retardation or other developmental disabilities, is the ABC chain, or Antecedent, Behavior and Consequence chain.

How many of you are familiar with the ABC chain?

*Option: ask participants who indicate that they are familiar with the ABC chain to describe it briefly - being prepared for the possibility that their information may be somewhat different from what is on the handout.*

*Distribute Handout 6D-1 and show Lecture Guide 6D-1. Use the Lecture Guide to highlight the following points on the ABC chain.*

Antecedent refers to a stimulus which precedes a behavior. The stimulus is consistently present before the behavior occurs and is likely to influence the behavior. In the chocolate cake example, the television commercial was the antecedent. It set up the chain of events that followed. Antecedents may include noise, fatigue, smells, or events. For example, a crowded room filled with people making loud noises may be the

antecedent for a client to withdraw and engage in self-stimulating behaviors or become agitated and disruptive. The stimulus may be internal or external, may be volitional or influenced by reflexes, chemical imbalances, medication, allergies, or seizures.

Behavior is the observable response an individual makes to a stimulus. In the example of the television viewer, the behavior was to stop watching television, search, prepare, and eat food.

Consequences are stimuli that occur contingently following a particular response. These payoffs, incentives, or motivators can be manipulated to encourage or discourage behaviors or skills. As we discussed in the module on the basics of changing behavior, the payoffs for the desired behavior must have more appeal or power than the payoffs for the undesirable behavior, in order for the latter behavior to be changed.

For people with mental retardation or other developmental disabilities, acting out behaviors may be their learned way of expressing pain, discomfort, anger, etc. Therefore, internal factors such as pain, frustration or an allergic reaction must be considered as well as external factors (such as staff or other client interactions, strong odors or allergens in the room where the behavior took place) before a program to decrease targeted behaviors can be implemented.

An important point to remember is that our behavior, and that of other individuals, serves a purpose. Suppose the television viewer is on a diet - let's pretend that it's a woman - and eating between meals is an undesirable behavior. The behavior may be pointing to a larger problem of low self-esteem, or she may be using food to stuff feelings that are too painful to express. We know that this pattern does not represent normal eating, because at no point in the sequence of events did she stop and ask herself, "Am I hungry?" In fact, asking this question could have been the intervention needed to prevent overeating.

To change behavior, it is necessary to identify the antecedents, observe the behavior, and determine consequences that will result in a desirable change in behavior rather than maintenance of the behavior. For example, our dieter may not lose the desired weight if she eats the chocolate cake. However, if being overweight reinforces the low self-esteem of the dieter, a conflict of payoffs is present. If low self-esteem is long standing, feeling good about oneself may not be enough motivation. To change undesirable behaviors it is necessary to determine interventions that will work, that is, interventions that will result in the desired behavior. Persistence is required to determine the consequences which will alter the person's behavior.

DEFINITIONS

Antecedent: A stimulus which precedes a behavior. The stimulus is consistently present before the behavior occurs and is likely to influence the behavior.

Behavior: The observable response an individual makes to a stimulus.

Consequences: Stimuli that are presented contingently following a particular response.



*Distribute Handout 6D-2 and show Lecture Guide 6D-2. Use the Lecture Guide to highlight key points on the components of assessment.*

Another approach to looking at behavior is functional analysis. Functional analysis recognizes that behavioral programs may need to look more broadly than the immediate apparent antecedent to the behavior. For example, although the TV commercial on chocolate cake was the immediate antecedent to the dieter's getting a snack, the behavior also was associated with how she was feeling that evening, her attempts at dieting (current and past), and her sense of self-esteem. Assessments in behavioral programs for people with mental retardation and other developmental disabilities need to consider all aspects of the individual's life in order to determine the most effective supports and interventions, including:

### **Scheduling and Structure**

- How well does the schedule and sequence of events match the person's individual "rhythm?" (We are not all morning people.)
- How structured and demanding are the situations? (Some of us do better with lots of structure than others.)

### **Opportunities for Choice and Control**

- Does the person have opportunities to make any choices? To have some control over the environment? (Most of us don't like feeling completely helpless or hemmed in.)

### **Communication**

- How does the person let people know wants and choices?
- How can we observe carefully what people are feeling? (Most people get really frustrated when they need something or are feeling strongly about something and no one seems to understand.)

### **Relationships**

- How does the person respond to the various people in his or her life?
- What kinds of interaction seem to help the person react more positively? (Most of us work better or enjoy being with some people more than others.)

## **FUNCTIONAL ANALYSIS COMPONENTS**

### **Scheduling and Structure**

- How well does the schedule and sequence of events match the person's individual "rhythm?" (We are not all morning people.)
- How structured and demanding are the situations? (Some of us do better with lots of structure than others.)

### **Opportunities for Choice and Control**

- Does the person have opportunities to make any choices? To have some control over the environment? (Most of us don't like feeling completely helpless or hemmed in.)

### **Communication**

- How does the person let people know wants and choices?
- How can we observe carefully what people are feeling? (Most people get really frustrated when they need something or are feeling strongly about something and no one seems to understand.)

### **Relationships**

- How does the person respond to the various people in his or her life?
- What kinds of interaction seem to help the person react more positively? (Most of us work better or enjoy being with some people more than others.)

The key to assessment is having a full picture of what is affecting the behavior of a particular individual. From that assessment, an individualized behavioral program plan can be designed that looks at all the ways to decrease the factors associated with the undesirable behavior and increase all the factors associated with the desired behavior.

The objective in decelerating (reducing) targeted behaviors is not solely the reduction of inappropriate behaviors. The objective is the deceleration of inappropriate behaviors and their replacement with positive and/or adaptive behaviors. Have you ever noticed how when you first try to eliminate negative thoughts from your mind, the number of negative thoughts you think actually increases? That's because you didn't replace them with positive thoughts. Not replacing negative thoughts with positive thoughts is a reason positive mental attitude programs don't work for many people. They only do half the required task, and the vacuum created is filled with more negative thoughts, rather than positive ones.

The same is true for behaviors. If an inappropriate behavior is not replaced with adaptive behavior, there is likely to be an increase in inappropriate behavior(s). For example, consider an individual who engages in compulsive talking with non-productive speech. A program which reinforces appropriate verbalization while reducing inappropriate verbalization should be implemented. This program could include behavior modification techniques which reduce the inappropriate verbalizations as well as to increase social interactions to provide opportunities to verbalize appropriately.

Behaviors do not exist in a vacuum. There are factors which precipitate and contribute to their occurrence. Uncovering the antecedents of behavior requires investigative work. Successful redirection of behavior depends on identification of the antecedents and the creation of strategies to effectively deal with the stimuli. If people are not making progress, are getting worse, or develop new bizarre behaviors in response to behavior modification strategies, the strategies must be re-evaluated. This is true even if the strategy includes nice, positive, socially acceptable types of reinforcers. If you examine an IPP and find that clients are not progressing, something is wrong with the program and further investigation is needed to determine what changes, if any, are being made and why they are believed to have change potential.

Let's look at an example of how inappropriate behaviors can be eliminated and replaced with adaptive behaviors.

Suppose a client engages in severe head-banging. A new psychologist comes to the facility and decides to implement a behavioral program to change the behavior. The first strategy implemented provided reinforcement of "no-head banging" with candy. The candy was offered intermittently during periods of non-head banging. (This type of reinforcement is called intermittent scheduled reinforcement.) If the client didn't bang his head for a period on the average of 15 minutes, he'd receive a piece of candy.



Over a couple of days the client began to make an association between head banging and candy. However, he increased the head banging, apparently in order to receive the candy. Obviously, this strategy wasn't working. The wrong association was made - that candy was a reward for head banging.

The next strategy tried involved hugging and praising the client when he stopped head banging. This, too, increased head banging. The client apparently thought that if he increased his head banging he would receive more hugs and praise. Other strategies were implemented until a successful one was found which incorporated reinforcement for not head banging, diversion to hand clapping whenever head banging began, and a planned program of tactile stimulation immediately prior to the times head banging had been found to occur. This example shows that the caregivers must be persistent and a variety of techniques must be explored to change behaviors. The facility could have just given up and said that this client was never going to stop head banging. Instead they persevered and found an intervention which was successful in reducing this potentially life-threatening behavior.

Some behaviors of clients are inappropriate only with regard to where the behavior occurs. For example, clients masturbating privately is considered far more adaptive and appropriate than masturbation conducted in public. Clients can be taught where and when behaviors are appropriate. Again, behavioral programs based on assessment can be used to accomplish these goals.

The video we're about to see looks at David, at a point in his life when he needed a great deal of help in dealing with his behavior.

*Begin Video 6D, Real Teaching - Part II.*

April 30, 1996

Anthony J. Tirone  
Deputy Director  
Health Standards and Quality Bureau  
Health Care Financing Administration  
S2-11-07 South Building  
7500 Security Boulevard  
Baltimore, MD 21244-1850

Dear Mr. Tirone:

Thank you for providing us with the opportunity to comment on the revised Conditions of Participation (CoPs) for intermediate care facilities serving people with mental retardation and related conditions (ICFs/MR). We congratulate you and your staff for developing a revised approach that is clearly more in keeping with contemporary notions of individualized supports and an attention to the outcomes of service interventions.

As you know, we have been working with your staff on a project exploring innovative quality assurance approaches around the country. You are currently in receipt of our draft report. In that report, we discuss possible directions for HCFA that would move even further toward an outcome-focused monitoring approach and conception of active treatment. With this in mind, we offer the following comments which should also be viewed in the larger context of our report.

Again, we feel that the changes proposed are positive and propose the following suggestions as constructive recommendations based on our broad contact with a range of people around the country concerned with the quality of care and services for people with mental retardation.

Sincerely yours,

Valerie J Bradley  
President



**➔➔➔➔➔➔➔➔➔➔➔➔➔➔➔➔**



## **CoP #2: Individuals Receive the Supports and Services Needed to Increase Functional Skills and Independence.**

Recommend rewording to read: Individuals Receive the Supports and Services Needed to Meet Personally-Defined Goals (or equivalent)

**(a) Active treatment definition** - Recommend that this section be re-titled: *Individualized Services and Supports (Active Treatment) Definition* and rewritten as follows:.

(1) Each individual must receive individualized services and supports (active treatment) based on personal goals, preferences and needs. The individualized active treatment program must be implemented consistently and include services and supports needed by each individual to:

- Develop increasing skills, especially those that promote greater independence, self-determination, and achievement of goals important to the individual;
- Develop and maintain satisfying relationships;
- Participate in community life;
- Exercise rights and responsibilities;
- Engage in productive activities; and
- Enjoy and participate in social, leisure and recreational activities.

(2) Active treatment/individualized services and supports must prevent or decelerate regression or loss of current optimal functional status.

(3) [same as current #2]

### **(b) Active Treatment Outcomes for Individuals**

Recommend putting as the first outcome the following:

"Each individual receives individualized services and supports (active treatment program) that is based on their person-centered plan, in which the individual and those who know him/her best have identified personal goals and the services and supports need to reach those goals."

Move #6 to follow this outcome.

### **(c) Active Treatment Facility Processes**

Revise #4 as indicated and put first:

"The facility implements a system to ensure that individual personal goals and desires are identified and form the basis of his/her plan of services and supports."

Add at end of #7:

"and to reduce the need for behavior management programs."

Add new process:

"Supports are provided to help individuals develop and maintain relationships, to increase their participation in community life, and to have experiences that increase their ability to make choices."

Revise #10 as follows:

The facility ensures that individual plans are modified to changed in response to the individuals specific accomplishments, *changes in individual goals and preference*, need for new programs, or difficulties in acquiring or maintaining skills.

## **CoP #3 on Behavioral Interventions**

### **(a) Outcomes for individuals**

Recommend adding:

"Each individual receives services and supports, including modifications of the environment, to reduce or eliminate the need for such interventions."

**(b) Facility process standards**

Recommend adding reference to the *specially constituted committee* as in current standards, and the following:

"The facility makes information on policies and any implementation of behavior management programs readily available to advocates and legal guardians of affected individuals and the state's designated Protection and Advocacy agency."

**Cop #4 Health**

**(a) Outcomes for individuals**

Recommend adding:

"Each individual participates in his/her own health care to the maximum extent possible and receives support in taking increased responsibility for maintaining the best possible health."

**(b) Facility process standards**

Recommend adding:

"The facility provides health education and other supports to individuals to assist them in developing and maintaining the best possible health and to increase their ability to take responsibility for their health care."

**Additional Comments**

We feel that Safety may not have enough visibility. It possibly could be combined with health, or added to Rights or addressed more clearly in CoP #5.

Recommend Individual Outcome:



**"Each individual receives services in a safe environment and supported in living safely."**

**Recommend Facility Process:**

**"The facility determines the safety needs for each individual, and provides education and supports on an individualized basis to promote each person's safety and their ability to take increasing responsibility for their personal safety."**



**APPENDIX E**  
**CUMULATIVE LIST OF ALL INTERVIEWEES**





**CUMULATIVE LIST OF ALL INTERVIEWEES**  
**(Asterisk \* indicates the individual offered comments about ICF/MR)**

**Colorado**

Developmental Disabilities Services:	Kerry Stern* Judy Ruth Lynne Struxness Heidi Cunningham
Association for Community Living:	Molly Markert* Tim Cairns* Linda Skaflen*
COPAR interviewer:	Dottie Balka*
Colorado Department of Public Health and Environment:	Sharon Haney* Terry Zamell Marilyn Waldschmidt
Legal Center:	Mary Anne Harvey*
People First of Colorado:	Anastasia Lawhead Jill Karet Douglas Nick Self-advocates from Boulder
Colorado Association of Community- Centered Boards:	Art Hogling* Chris Collins*
Jefferson County CCB:	Jane Byron* Judy Pauley* Casey Glaser*
Johnstone Developmental Center:	Julie Bielensen*
Foothills Developmental Center	Deborah Lapp Erin Strack Phyllis Freeman Connie
Good Shepherd ICF/MR:	Cindy Warren* Barbara*
Developmental Disabilities Council:	Don St. Lewis*

**Oklahoma**

Developmental Disabilities:	Jim Nicholson*	Gwen
McClain*		
Services Division	Dennis Bean*	David
Goddell*		
Moore*	Bob Nort*	Priscilla
	Alice Gord*	Leslie Parks*
	Makela Bishop*	Sandy
	Leslie	Bonita
	Deborah	
Governor's Performance Team:	Greg Thomas	
Oklahoma City providers:	Judy Goodwin*, OCP	
	Terry Vaughan*, Center of Family Love	
	Belinda Stevens*, Edmonds ARC	
Department of Health:	Linda Wilkerson*	
Oklahoma AIM:	Brenda Zyzack	Sandra, staff
monitors	3 consumer monitors	4 parent
Tulsa providers:	Frank Hackett, VOA	Kay, VOA
Oklahoma AIM:	Deanne Aimsley	Chris
	Mary Ann Duncan	John Gajda
monitors	1 consumer monitor	5 parent
DDSD Area 2:	Gay McMillen	Sammye
Hitchye	Tami Kelley	Harry
DHR Office of Client Advocacy:	Chase Gordon	
Oklahoma State University:	Barbara Murray	Richard
Dodder	Pat Bell	Amanda
Fullerton	3 surveyors	

### Oregon

Office of Developmental:	James Toews*, director
Disabilities Services	Mary Lee Fay*, QA manager
	Sean McMullen
	Sue Stoner
	Julie Beaton



ODDS Licensing staff:	Holly Robinson Terry Ritner Sue Birge Barb Southard	Roland Brown Jim Ransom Gretchen Thompson
Advocates:	Charlotte Duncan*, DD Council Katherine Weit*, DD Council K. Meeks*, Arc of Oregon Janna Starr*, Oregon Advocacy Center	
Oregon Technical Assistance Corporation:	Mike Maley* Ron Spoelstra*	
Fairview Training Center:	Chuck Farnham* Laurie Lindberg* Audra Hamilton* Jimmy Clark*	
State Training Center Review Board:	Penny Spaccorattelli*	
AIM Monitors:	Phyllis Crocker Marilyn Bell Betty ... Marty McKean, staff	Evelyn Henderson Teli Ragsdale Candy ... Julie Cumiford, staff
Providers:	Zellee Allen Jan Kral Vicki Harbaugh Dan Guevara Bill Adams	Ken Becker Anson Bell Rick Curren Roger Hassenpflug
Paradigm Systems:	Darla Wilson	
University of Oregon	Rob Horner David Mank	Billy Ard
Oregon Rehabilitation Association:	Tim Kral	
Marion County DD agency:	Mike Sedlock,	
Senior and Disabled Services Division:	Shirley Saries* Ruth Tooze*	Alice Wagner*

#### **Utah Site Visit Interviewees**

Division of Services to People with Disabilities:	Georgia Baddley* Sue Geary* Renae Taylor* Nonie Lancaster	Sharon Yearsley Sue Marquardt* Robyn Mendenhall* Sylvia Wright
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Provider, designed survey:	Dave Hennessey	
DHS Division of Licensing:	Alan Hayward	
Utah Health Department:	Ann E. Lee* Deb WynkoopGreen* Allan Jenkins*	Sara Sinclair* Helene Middleton*
Salt Lake City providers:	Joyce Halling* Marsha Parisi Phil Shumway	Ann Walker John Harbert
Advocates: :	Cathy Chambliss*, GCPD Eric Mitchell*, Legal Center Bev Adcock*, ARC Deborah O'Dell*, DSPD	
Utah State Developmental Center:	Keith Stroud* Jim Jex*	Karen Clarke* Vicki Gurney*
USDC volunteer monitor:	LaReal Mace*	
Mental Retardation Association of Utah (parent advocates):	Dean Robinson* Carola Zitzmann*	Claudia Miles*
Provo providers:	Cathy Richins* Bonnie Duval* Richard Pace	Kenneth Ekong* Gerald Nebeker* Mary Pace
Western Region DSPD staff:	Eve Hendrix Terri Jensen	Bob Brewer Ana Manent
Western Region vol. monitor:	Mary Gritton	
Western Region families:	Joyce Parker Judy Moody	Carol Allen
Legislators:	Brent Haymond* Judy Ann Bethmayer*	Charles Stewart*
Central Region DSPD staff:	Linda Worsley Ron Niederhauser	Ken Tidwell
Central Region vol. monitor:	Marilyn Williams	
Central Region families:	Bobbie Saunders	Mary Paulsen
Legislative Fiscal Office:	J. Winslow	

#### **North Dakota (telephone only)**

North Dakota (Grafton) ICF/MR: Joanne Steffen

#### **Wyoming**

Division of Developmental Disabilities:	Jon Fortune* Robert Clabby*	Nancy Riley* Wayne Johnson*
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	Leo Urbanek* Cheri Moon*	David Haines* Ramona Doidge*
University Affiliated Program:	Ken Heinlein*	
Health Quality Planning and Program Evaluation:	Jane Taylor*	Cheryl Gerrish*
DD Council:	Happy Weston*	
Magic City Enterprises:	Jack Firestone Sharron Kelsey	John Abas
The Ark - (Laramie):	Darryl Cooper Jeff Gardner Shelle Glassman Ark parents and consumers	Terry Cooper David Heath Kathryn Paxton
Protection & Advocacy:	Jeanne Thobro*	Danny Wilde*
Arc of Cheyenne, Arc of Casper:	Self-advocates and family members	
Legislator:	Jayne Mockler*	
Community Entry Services:	Shawn Griffin* Bill Davis Joe Howard Pat Harris John Fontaine	Brenda Apadaca Jennifer Johnson Sis Nelson Gary Hudson* Todd Wright
Mountain Regional Services:	John Holderegger	
Weston Class Advocates:	Elva Laird* John L. "Louie" Gillette*	
Legislator:	Clarine Law*	
Wyoming State Training School:	Robert T. Clabby* Randy Howdyshell* Hermann Fischer* Linda Gudmundsen* Becky Nelson* Beverly Swistowicz* Maribeth Kendall* Cody Kaper* Sue Cloninger* Jim Lyonn* Anita Wilson*	David Brunner* Cliff Mikesell* Charlotte White* Becki Harris* Patricia Riddle* Denise G. Foss* Dawn Parkins Green* Tony Martynuska* Mike Auband* Mary Lin Johnson* Dennis Yort*



## **Massachusetts**

Department of Mental Retardation	Phil Campbell*	Dorothy Mullen
	Ron Sanfield	June Rowe*
	Terese LaCroix	Gail Grossman*
	Laurie Anderson	Elliott Berusch*
	Mary Ann Brennan	Gerry Morrissey
	Connie Lehr	Mary Cerreto*
	Rosemary Bevins	Pam Nicholson
	Jeanne Adamo	Michael Kendrick*
	Jean Tuller*	Dick Cohen
	Paul Antonellis	Angus Capie
	Hans Toegel*	Melissa Probst

Boston Area Advocates /Family Members:	Jean Whitney Thomas	Michael Brooks
	Jerry Kelly	Betsy Clausen
	Lucy Chansky	Jody Williams

Boston Area Providers:	Steven Hoy, Humanity House
	Nancy Hargreaves-Silver
	Diane Iagulli, Delta Project
	Todd Kates, UCPA Metro Boston
	Jennifer Hight, Bay Cove Human Services
	Barry Schwartz, Vinfen
	Virginia Connolly, Beaverbrook STEP

Boston Area Consumers, Family and Direct Care Staff  
TXIX Surveyor  
Department of Public Health:

Jack Hart\*

Wrentham Developmental Center Staff:	Nicholas D'Alusio	Dean Nowland
	Paul Blake	Joanne Cumming
	Cindy Shephard	Joe Kavihaug
	Pat Nichols	Mary O'Leary
	Bruce Ziegler	

Wrentham Developmental Center QMRPs	Ann Costa
	Paul Maccaione
	Janet Price
	Dean Nowland
	Lady Lavendar Lee

Southeast DMR Regional and Area Staff:	Rick O'Meara	Phil Tully
	Paul Clifford	Randy Webster
	Mark Sanderson	Mary Beth Vargus

Margie Masse  
Rick Cavicchi  
Marureen Pereira  
Jack Yates

Dianne Rodrigues  
Cecelia Roberts  
Kathleen Catano

**Southeast Regional Providers:**

Donna Sabecky, Behavioral Associates of MA  
Peg O'Keefe, Community Connections  
Jim Ross Community Partnerships  
Janet Butler, Community Systems, Inc.  
Richard McNally, New Bedford Harbor Services  
Ann Shore, C.P. of South Shore  
Suzanne Raffa, Reach, Inc.  
William Kelley, Beta Community Service  
Karen Seals, Amego, Inc.  
Steve LeClair, Randolph Occupational  
Sheila St. Aubin, Westport Associates  
Paul Hudson, Kennedy-Donovan

**Consumers:**

Susan Harrington, QUEST Volunteer  
Mark Wotjonski, Future QUEST Volunteer

**DMR Western Regional Staff:**

Steven F. Bradley*	William Zimmer*
Rick Huntington*	Denise Barci*
Lee Schmidt*	Bruce Brewer*
Doug McAllen*	Betsy Noonan*
Barbara Morrel*	

**QUEST Surveyors:**

Greg Shumway*	Donna Labello*
Neil Lazar*	Marty Rachels*
Andrew Fershette*	Bob Sinopoli*
Philiss Seaver*	Jim Ciullo*

**Providers:**

Ken Singer, Berkshire County ARC  
Janet Ryan Roman  
Terry Blanchard, Commonwealth Community Services  
Barbara Pilarcik, Association for Community Living  
Rich Toscano, Integra, Inc.  
Ruby Moore, New England Business Associates

**Families and Advocates:**

Jim Johnson, Chair, Local Advisory Board and Parent  
Julie, Region I Advisory Board - Family member served by Region III  
Joyce, Chicopee Advisory Board

## **Missouri**

Certification Project Team:	Kate McClain Meg Hutsler Gary Davis	Donna Haley Cori Brown
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University of Missouri, Kansas City (UMKC-UAP)

*Also present:*

Kansas City Regional Center:	Gail Clair Charles Wheeler
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St. Louis Regional Center	Anita Contreras Nancy Shrewsbury
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Sikeston Regional Center	Kim Crites
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Allied Groups:	Carl Calkins, Director UMKC-UAP Kay Conklin, Director, Missouri Developmental Disabilities Planning Council Bob Fain, Chair, Missouri Protection and Advocacy Board Shawn de Loyola, Missouri Protection and Advocacy Board
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Regional Quality Improvement Staff:

St. Louis Regional Center	Anita Contreras Nancy Shrewsbury
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Sikeston Regional Center	Kim Crites
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Springfield Regional Center	Cindy McKean Patty Tapp
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<i>Also present</i>	Bob Story*, Parent, Certification Committee Kate McClain, Quality Enhancement Coordinator Meg Hutsler, Certification Consultant Gary Davis, Certification Consultant Mary Carrick, Certification Project Committee Member
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Certification Steering Committee:	Mary Carrick Jean-Paul Bovee Molly Allen Bob Story
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DMRDD Management Staff:	Melinda Elmore Bob Bauermeister* Bob Thompson*
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Gail Clair\*  
Ray Griffel\*  
Jim Magruder\*

*Also present:*

Cori Brown  
Donna Haley  
Kate McClain  
Crystal Amini-Rad

**Family Members and Advocates:**

Missouri Advocates for Individuals with Developmental Disabilities (MOAIDD) Grandparent Jim Spradling

**MOAIDD:**

George Boyle  
Mike Hanrahan  
Dick Hosty  
Judy Cross  
Marilyn Spradling

**Sherwood Center:**

Marilyn Stubbs

*Also present:*

Cori Brown  
Donna Haley  
Kate McClain

**ICF/MR Administrators:**

Bob Bauermeister\*  
Bob Thompson\*  
Ted Allen\*

*Also present:*

Cori Brown  
Kate McClain

**Core Project Management Team on Quality Enhancement Strategies:**

Denine Hunt  
Ron Torner

**Core Project Management Team on Quality Enhancement Strategies (continued.):**

Ted Allen  
Louise Stefanowicz  
Molly Allen  
Gail Clairtve

*Also present:*

Crystal Amini-Rad

**Division Director:**

Greg Kramer\*

**Certified Agencies:**

St. Francois County Group Home      Leanne

Willows Way      Kim  
Dawn

ACD Accredited Agencies:

Judevine Center      Maura

St. Louis ARC      Kathy Meath

## **NEW YORK**

Office of Mental Retardation and  
Developmental Disabilities Staff

Harold Hopkins\*  
Thomas Cuite\*  
David Picker\*  
Tom Richards

Surveyors:

Ron Rzepnicki\*  
Judy Trent\*  
Tom Articola\*  
Dan Caryl\*

Mike Savery\*  
Joann Caldara\*  
Bob Brooke\*  
Sue Brisley\*

## **PROVIDERS**

Albany ARC:

Larry Fuld  
Andy MacKenzie  
Deborah Elcock

Rome DDSO:

Steve Smits\*  
Nancy Straub\*  
Sharon Falke\*  
Art Holmberg\*  
Sharon Sherman\*

George Schlotterer\*  
Diane Dumas\*  
Gil Palladino\*  
Gail Rushford\*  
Bill Bonaro\*

AABR:

Peter Maramaldi\*  
Jane Carnacchio\*  
Kathryn Flood\*  
Doreen Atwell\*

Saratoga ARC:

Patrick VanSlyke

Consumers and Advocates:

Helen DeVecchio  
Marisol Diza  
Kermit Augustine  
Marcie Goldstein  
Rain Rippel

OTHER:

Bill Combes, New York State Commission on the  
Quality of Care  
Sarah Anderson, New York State Association of  
Community and Residential Agencies



## ICF/MR PROVIDERS SURVIVED

Res-Care Inc.  
Houston, Texas

Helen G. FitzSimmons

Independent Options, Inc.  
Corona, CA

Rebecca Helgeson

Community Support Services, Inc.  
Biddeford, Maine

Rory Robb  
Susan Church  
Ann Miller

Miami Cerebral Palsy  
Residential Services, Inc.  
Pembroke Park, Florida

Marta E. Morlin

OHI  
Hermon, Maine

Bonnie-Jean Brooks

**APPENDIX F**  
**COMBINED REFERENCES**  
**(TASKS A & B)**





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